IF I LOSE CAPACITY, WILL MY ADVANCE DIRECTIVE BE HONOURED?

Submitted by: Annie Christine Meates

Student ID: 738546693

A thesis submitted in fulfilment of the requirements for the degree of Master of Laws,
The University of Auckland, 2022

(*word count: 33,887)*

Abstract

In New Zealand any mentally competent person aged 18 years and over can complete an advance directive [AD] to receive or refuse health treatment at a future time when they no longer have capacity. This paper identifies what current legislation informs an AD, and how and where an AD is used, with an emphasis on people over 65. For Māori, as tangata whenua, te Tiriti o Waitangi obligations, relationships, Māori values and self-determination (tino rangatiratanga) are relevant in this discussion where it involves older Māori kaumātua and kuia. While legislation establishes the legal authority for an AD, a second pathway has emerged within the health sector with the development of Advance Care Planning [ACP] for health consumers, usually with terminal health conditions. An AD is activated by a determination that a person no longer has the requisite capacity. The outcome has major consequences for the person deemed not to have capacity; they are then unable to exercise their right of self-determination with decisions made for them by others, usually on a best interest basis. The principle underpinning the AD is individual autonomy; this means that if an AD is valid and applicable it must be followed. This principle is supported by domestic law, and international law and conventions. While the principle of autonomy may not represent the cultural practice or beliefs of everyone in their end-of-life care, research in New Zealand and internationally indicates a strong desire in the older age group to retain some sense of self and self-determination in end-of-life choices. Notwithstanding this, in practice the number of ADs remains low. Indications are that in the health care sector there is a structured system for ACP that includes ADs which operate under the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 [HDC Code]. An AD, whether made under the legal or health systems, operates in accordance with the common law. To ensure an AD will be honoured, certainty and confidence is required within an effective statutory framework where both legal and health can navigate, with a clear definition of capacity and guidance as to form, which will protect a person's rights, and preserve autonomy, dignity and a future vision of dying well.

Acknowledgements

Thank you to my supervisor, Professor Mark Henaghan of Auckland University who was immediately enthusiastic and positive about the topic for this paper. This positivity has continued throughout with support, guidance, knowledge, discussion, insight and critique which has made my journey of completing this paper a more enjoyable one.

I have used the assistance of a third party for the purposes of proofing purposes only and there has been no third-party contribution to the intellectual content of this thesis.

Table of Contents

Introduction

"Two things awe me most, the starry sky above me and the moral law within me."
Immanuel Kant (1724-1804)

New Zealand's ageing population is steadily increasing[1] and will mirror the growing worldwide numbers of people with cognitive impairment (in particular Alzheimer's disease and dementia)[2] who no longer have capacity to make their own life decisions, and with no prospect of returning to a life under their own control.[3]

For people who have mental capacity there is no issue; they make their own choices about their own lives. For a person deemed to no longer have capacity, and in particular an older person, if there is not an advance directive in place setting out what health treatments they wish to receive or refuse, who then will make that decision for them? Will a 'best interest' approach reflect what they may have chosen themselves?

The Protection of Personal and Property Rights Act 1998 [PPPR Act] provides for a person with capacity to appoint a substitute person, an attorney, to act for them in the future, if and when they lose capacity. Within this legislation the attorney is required to have regard to any AD made.[4]

This paper examines the AD in New Zealand and how and where it operates.[5] This inquiry, initially defined as a legal inquiry, expanded immediately into the health arena where the advance directive has been placed within the HDC Code, highlighting the medico-legal tension that exists in our current legislation, and our lack of development in capacity law. In comparable international jurisdictions, mental capacity law has been developed within a strong statutory framework supported with comprehensive guidelines; these provide a streamlined adjunct between law and medicine that provides oversight and protection for people who lack capacity.

---

[1] Department of statistics <stats.govt.nz/information-releases/national>.

[2] Ma'u E and others *Dementia Economic Impact Report 2020* (University of Auckland; Prepared for Alzheimer New Zealand, September 2021).

[3] Govert den Hartogh "The Authority of Advance Directives" in Denier Y, Gastmans C and Vandervelde A. (eds) *Justice, Luck & Responsibility in Health Care* (Library of Ethics and Applied Philosophy, London, 2013) 167 at 168.

[4] PPPR Act, s 99A.

[5] Previously known as a 'living will'.

For an AD to reach the common law jurisdictional threshold, it must be valid and applicable in the circumstances.

The legal authority for the AD is in the PPPR Act,[6] in name only. It is the HDC Code where the AD is given definition and authority, being incorporated in the recent development of ACP within the health arena. The writer argues that in the area of capacity law, New Zealand has fallen behind other international jurisdictions, and has an inadequate legal framework.[7] This has resulted in the AD developing along separate legal and health pathways. These pathways are disconnected with insufficient legal oversight, guidelines and dialogue to ensure patient rights are fully protected.

The different legal and health pathways for an AD are identified under the PPPR Act and the HDC Code, with the capacity test thresholds in New Zealand compared to the recent international development in mental capacity law. This development includes the Mental Capacity Act 2005 (UK) [MCA], the Mental Capacity Act (Northern Ireland) 2016 [MCANI] and Queensland (Qld) legislation.[8] Each have guidelines that clearly define capacity and connect capacity with ADs and end-of-life care.[9] The ethical considerations around the AD are discussed.

When compared to the robust statutory framework and guidelines in place in other international jurisdictions around capacity law, ADs and enduring powers of attorney [EPOA],[10] there are challenges in New Zealand around the drafting and use of ADs and EPOAs. Lessons can be learnt from these comparisons; in addition, for New Zealand there are obligations to an indigenous people and a multicultural society. In particular for Māori there are cultural values, beliefs and practices around death and dying. When engaging with older Māori with dementia, language and culture become very important, as do the themes of connection (tūhononga) and self (whaiaro).[11]

---

[6] PPPR, s 99A.

[7] Law Commission is to undertake a review of the law relating to adult decision-making capacity, with public consultation in 2022.

[8] Powers of Attorney Act 1998 (Qld) and Guardianship and Administration Act 2000 (Qld).

[9] The terms ‘competent’, ‘capacity’ and ‘mental capacity’ are used interchangeably in this paper, with the common meaning of having capacity, a degree of capacity or a loss of capacity. The terms ‘advance directive’, ‘advance decision’ and ‘advance health directive’ (Qld) all refer to a future refusal of health treatment; the same concept as the AD.

[10] MCA and MCANI have lasting powers of attorney.

[11] Oliver Menzies and others “He Tuhonoga Whaiaro: A Kaupapa Māori Approach to Mate Wareware (Dementia) and Cognitive Assessment of Older Māori” (2021) Journal of Applied Gerontology 1 at 1.

While the writer is a legal practitioner and the initial focus of this study was intended to be around the legal aspects of the AD, the inquiry had to broaden due to the development of the ACP and the placement of the AD promoted within that structure. The analysis in this study is from a socio-legal perspective.

In the practice of law, if asked to draft an AD, there is no guarantee that the document used will be sufficient to achieve the intended result. The legislation is confusing, the format unclear and the terminology somewhat muddled. In the past few years, the term 'advance directive' appears only to be mentioned with EPOAs and Wills in legal seminars. In the writer's view an AD is a very important document that allows a person to retain some control over their future health decisions, and is increasingly important for people aged 65 and older [65+], the 'baby boomer generation'.

The AD inquiry begins with statistics around the increasing life expectancy and an ageing population. For many there is an emerging reality that while a person may live a longer life, there may, as a result, be a longer period of declining health and cognitive impairment.[12] The structure and use of the EPOA within the PPPR Act is assessed with limitations highlighted.

The AD is explained within the PPPR Act, the HDC Code and the common law; this framework is compared with other comparable jurisdictions. The rise and development of the ACP in New Zealand is identified with recent published studies around their use. The loss of capacity forever changes a person's life. The PPPR Act sets a number of thresholds in determining the ability of a person to make their own decisions. There are six different capacity tests to be applied in varying circumstances within this Act, and comment is made on other international jurisdictions that have a single definition for determining capacity. Legal ethics and medical ethics are shown to have a different philosophical emphasis, and the arguments around the principle of autonomy, loss of capacity and future care choices are discussed. Recommendations for improvement are outlined.

---

[12] Kate Grundy "Dying Well" (ACP training paper, Christchurch, May 2021) at 5.

To answer this thesis question, ‘If I lose capacity, will my advance directive be honoured?’, this paper critiques and analyses our New Zealand position against other international jurisdictions, and highlights the need to develop a new landscape for capacity law and its practical application.

Statistics

In assessing the question 'If I lose capacity will my advance directive be honoured?' the scenario where an AD may be used is likely to be quite unremarkable. The person is likely to be elderly, possibly with a progressive medical condition and assessed as no longer having capacity to make choices about their care. The person would, when competent, have completed an AD which represents his or her wishes or directives around their care treatment at a future time as they move towards their 'dying well'.[13]

There has been a significant increase in life expectancy over a period of time due to a number of factors such as vaccinations, the control of infectious diseases, a reduction in tobacco use, and an increased ability within medical science to sustain life for a longer period for people with a terminal illness.[14] The increase in life expectancy, however, does not necessarily bring years of good health, and for many older people it may be a longer life, but in declining health with their later years lived with a disability or cognitive impairment.[15]

There are a number of conditions that may lead to cognitive impairment and a loss of capacity, including Parkinson's disease, stroke, Alzheimer's disease and various types of dementia. For the elderly in care, it has been noted that there is a high prevalence of common psychiatric disorders such as depression, anxiety, psychosis, delirium and dementia.[16]

What do the statistics show?

The ageing population growth is accelerating, driven by rapid increases in life expectancy. The statistics show a growing number of people 65+ worldwide is expected to grow from an estimated 524 million in 2010 to nearly 1.5 billion in 2050.[17]

---

[13] At 15.

[14] Thomas, Cordelia "Refusal of medical treatment by way of advance directives" (2001) 3 BFLJ 233 at 233.

[15] Vladimir Stevanovic *Independent Life Expectancy in New Zealand* (Ministry of Health, 2013) at v.

[16] Matthew Croucher "Psychotropic medications for elders in residential care" (2008) 121(1274) NZMJ at 7.

[17] World Health Organization *Global Health and Ageing* (US National Institute of Aging, Geneva, 2011).

In New Zealand between 1981 and 2013 the number of people 65+ almost doubled from 9.9% of the population (309,795) to 14.3% of the population (607,032). This number is expected to rise to 23.8% of the population by 2063.[18]

While these numbers appear large when discussed from a worldwide prediction to 2050 and a percentage rise in New Zealand to 2063, the figures can be dissected further to apply to now. In 2021 54,370 people turned 65 years, making up a combined total of 819,600 people aged 65+.[19] There has also been a significant increase in the 85+, and 95+ age groups; with a substantial increase expected to continue.[20]

The implications and impact of living longer

With modern medicine has come the ability to cure and manage many diseases, leading to prolonged life and delayed death.[21] The possibility of living a longer life with declining health and cognitive impairment for a longer time will impact the decisions a person may make about what they might chose at that future time.

There are certain patterns of illness trajectories at a person's end-of-life that can be expected. A person dying suddenly or from an accidental death is rare,[22] most people are dying of and with chronic conditions rather than acute conditions.[23] In the trajectory for most cancers, life will carry on for a time with a short period of evident decline before death. With organ failure (mostly including heart and lung failure) there will be long-term limitations for the person over a period of time with intermittent serious episodes before a sudden decline to death. With frailty and dementia there is usually a prolonged and dwindling health progression to eventual death.[24]

The impact of the increase in the older population can be seen in New Zealand's health services with increasing financial pressures in the distribution of healthcare resources.[25]

---

[18] Stats NZ "2013 Census Quickstats about people aged 65 and over". <stats.govt.nz/infographics/people-aged-65-plus-living-in-new-zealand>

[19] Stats NZ "National population projections, by age and sex, 2020(base)-2073". <nzdotstat.govt.nz>

[20] Stats NZ "Historic estimates and national population projections, 2014(base)-2068". <catalogue.data.govt.nz>

[21] Malpas, Phillipa J "Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand" (2011) 37(5) J Med Ethics at 285 at 285.

[22] Grundy, above n 14, at 5.

[23] Malpas, above n 22, at 286.

[24] Grundy, above n 23, at 5.

[25] Malpas, above n 24, at 286.

The older population is growing faster than the younger population with older people using more health services than younger people. In 2015/16, the 65+ age group were using 42% of health services while making up only 15% of the population with projections that this could increase to 50%.[26] It has been noted that medical care for the elderly is becoming the core activity of general hospital-based medicine and surgery, and the impact will greatly affect access to younger adult surgery and medicine in the future.[27]

The extent of this issue can be seen in the 2007 audit from data provided by the Canterbury District Health Board's [CDHB] patient management system clinical database of admissions to Christchurch Public Hospital over a one-week period.

During that week 62% of general medical hospital admissions were people aged 65+, and 32% of those admissions were for people aged 80+; for acute admissions for the entire hospital over the week 41% were aged 65+.[28] The growing and ageing population is placing increased financial pressures on healthcare resources where the distribution of healthcare spending is unsustainable.[29]

The impact of dementia on this ageing population has been highlighted in the Dementia Economic Impact Report of 2020 [DEIR 2020]. Dementia is an increasing problem with its many areas of impact and cost for people, society, health care and finance. The key findings included an estimated 69,713 people with dementia (1.4% of the total population) of which 63,525 were aged 65+ (8% of the 65+ population), an increase of 11.9% since the DEIR 2016. The number of people living with dementia is projected to more than double to 167,483 by 2050 (2.7% of the total population and 10.8% of the 65+ age group). In 2020 a quarter of people who died in New Zealand had a diagnosis of dementia at the time of death. Māori, Pacific and Asian populations will comprise a greater proportion of all individuals living with dementia in the future years due to the projected growth in their younger populations.[30]

---

[26] Ministry of Health "Older people's health data and stats". <health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/older-peoples-health-data-and-stats/dhb-spending-services-older-people>

[27] Mathew Croucher "Geriatric medicine is becoming the core of hospital business" (2010) 123(1317) NZMJ 7 at 7.

[28] At 7.

[29] Malpas, above n 26, at 286.

[30] Ma'u, above n 2, at 31.

While the DEIR has completed reports in 2008, 2012, 2016 and 2020 on dementia highlighting the need for epidemiological studies to be completed in New Zealand to determine the prevalence of dementia, no such studies have been completed and international data is relied on. New Zealand has yet to develop a plan that addresses the current and future issues around dementia.

In 2017 the World Health Organization [WHO] called on the 194 member states to produce a national dementia plan or strategy by 2025 as part of the WHO's Global Action Plan. Each developed plan would include steps for implementation and monitoring, and research around the prevention, diagnosis, treatment and care of people living with dementia.[31]

The ageing population statistics, both worldwide and in New Zealand, will impact public policy considerations and government health spending. For the health and legal systems there are many issues that need to be addressed to ensure that people without capacity are protected, and that we have a legal framework that will provide clarity and certainty for all involved.

---

[31] At 27.

Enduring Powers of Attorney

The PPPR Act and enduring powers of attorney

In New Zealand, the legislation covering future decision-making and capacity is primarily found in the PPPR Act and the HDC Code.[32]

The PPPR Act came into force on 1 October 1988 replacing Part 7 of the Mental Health Act 1969 and The Aged and Infirm Persons Act 1912 providing an adult guardianship for those people who had previously been the subject of mental health law, and the aged.[33] Prior to this there had been no ability to provide for the adult guardianship and property management for people unable to manage their own affairs.[34]

A standard power of attorney would terminate when a person could no longer understand the consequences of the power, but this was often at the time when it was most needed.[35] The High Court had the power to appoint a manager to handle a person's property, but it was not able to deal with personal matters.[36] The PPPR Act was seen to be progressive at the time, as it moved from the paternalistic best interest model and gave greater emphasis to more autonomy in decision-making.[37] The long title of the Act states it is for the protection and promotion of the personal and property rights of persons who are not fully able to manage their own affairs.[38]

Who is the PPPR Act for?

The PPPR Act provides statutory protection for people over 18 years with specific provisions for people between 16 and 18 years who have no living parent or guardian, have never been married or in a de facto relationship, and who are unable to manage their own affairs.[39] This appointment can either take effect immediately and is not revoked if the person becomes mentally incapable, or comes into force when they become mentally incapable.

---

[32] Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Wellington Press 2020) at 22.

[33] Clare Barrett (ed) *Incapacity* (looseleaf ed, Westlaw) at [PPIntro.01].

[34] *Sylvia Bell Protection of Personal and Property Rights, Act and Analysis* (Brookers Ltd, Wellington, 2012) at 2.

[35] At 36.

[36] Barrett, above n 34, at [PPIntro.01].

[37] Bell, above n 35, at vii.

[38] The Protection of Personal and Property Rights 1998 [PPPR Act], Long Title.

[39] PPPR Act, s 6.

The PPPR Act has two pathways in relation to capacity and documents that can be used for substituted decision-making. The first, in the Family Court with orders made upon application; the second, under the EPOA for the appointment of an attorney for a future time when the donor (the person appointing an attorney) no longer has capacity.

The PPPR Act and the Family Court

Where a person is deemed to no longer have capacity and does not have an EPOA for their personal care and welfare, an application can be made to the Family Court for the appointment of another person, an attorney, to act for that person as a welfare guardian. The Family Court has the statutory authority to make a number of personal orders including a s 10 personal order, a s 11 order to administer property, and a s 12 appointment of a welfare guardian.[40]

In the Family Court the presumption is that the person has capacity until the contrary is shown.[41] The applicant may need to show not only an impairment and incapacity or incompetence, but also that the effect of the impairment is such that intervention is necessary.[42] The presumption of competency is emphasised by the United Nations Convention on the Rights of Persons with Disabilities [CRPD], which New Zealand ratified in 2008.[43]

The Court's primary objective is to make the least restrictive intervention, having regard to the degree of the person's incapacity, to encourage that person to participate to the greatest extent possible.[44]

The person who is the subject of an application to the Family Court is known as the subject person. The person appointed under the application is known as the welfare guardian. A lawyer is appointed to represent the subject person,[45] and to report to the Family Court on matters such as whether the subject person should be served and attend the hearing, whether further medical evidence is required, whether further consents to the

---

[40] The PPPR Act also extends s31 property orders to include Kai Tiaki Trusts, (31A& 32B, 41), Trustee corporations (32) and the role of the Public Trust (s39, 40, 46, 51).

[41] PPPR Act, s 5.

[42] *Re Tony* [1990] 5 NZFLR 609 at 624.

[43] Bell, above n 38, at 50. United Nations Convention on the Rights of Persons with Disabilities A/RES/61/106 (opened for signature 30 March 2007, entered into force on 03 May 2008).

[44] PPPR Act, ss 8(a) and 8(b).

[45] Bell, above n 44, at 301.

appointment are required from family/whanau, what aspects of the personal care and welfare are sought, and the suitability of the proposed appointee.[46] In 2020, there were 2,227 Welfare Guardian applications made to the Family Court (2,042 in 2019).[47]

Orders made in the Family Court are given an FAM identifying number and are usually made for either a three or five-year period. The Court normally appoints one welfare guardian and there is no express power to appoint an alternative guardian to take over on death, absence or incapacity of the main guardian.[48] The PPPR Act retains High Court jurisdiction pursuant to s114 of PPPR Act. In *Re W* the High Court noted:

> *"it may well be that the restriction on the power of the Family Court imposed by s18(1)(a) ... may have been the reason for the express preservation of this court's jurisdiction contained in s 114 of that Act."*[49]

To establish the jurisdiction, the question is whether there is no longer competence. In *KR v MR*, Miller J observed:

> *"The question of capacity to make the decision is the subject of an application (under the Act) is a threshold question and must be considered in every case; because jurisdiction to make an order depends on it."*[50]

A medical report in relation to capacity is filed with the Court application. If there is any doubt, further inquiries would be made and an updated medical report or second opinion sought. The Family Court considers the appointment of a welfare guardian a last resort with a conservative stance adopted.[51] The making of such an order has serious consequences for the subject person.[52]

The lack of capacity must relate to the particular aspect of the person's care and welfare that will be the subject of the order. In *Re F (No 3)*, the judge found that the elderly woman suffered from delusions and her refusal to undergo surgery for breast cancer led to the

---

[46] Family Court Minute brief for lawyer for subject person (3 December 2021).
[47] Ministry of Justice letter (Ref: 90590, number of applications filed under PPPR Act, by application type and year, 2016-2020) (obtained under Official Information Act 1982 Request to A Meates).
[48] B Atkin (ed) Personal Orders (looseleaf ed, Lexis Nexis) at [7.823].
[49] *Re W* [1994] 3 NZLR 605 at [33]–[36].
[50] *KR v MR* [2004] 2 NZLR 847 at [50].
[51] Atkin, above n 49, at [7.823].
[52] Bell, above n 46, at 56.

next inquiry for the Court to determine what order and what level of intervention was required.[53]

The legal burden of establishing a lack of competence falls on the person alleging it; the evidential burden then passes to the subject person to rebut it.[54] The standard of proof required is on the balance of probabilities.[55]

The PPPR Act and EPOAs

In 2001, the New Zealand Law Commission published a report entitled Misuse of Enduring Powers of Attorney.[56] The inquiry was undertaken following concerns raised by Aged Concern about a lack of protection and inadequate safeguards for the elderly and the disabled. The concerns raised included neglect, a lack of consultation, embezzlement and bullying.[57]

The PPPR Act 2007 amendments

EPOAs were introduced into the legislation with the insertion of Part 9 Enduring Powers of Attorney, Sections 93A to 108AAB.[58] The presumption of competence under Section 93B can only be displaced by a certificate from a relevant health practitioner.[59] An EPOA can be revoked if it is demonstrated that the donor (the person making the appointment) lacked capacity when he or she executed the power. For the EPOA donor, there does need to be a general understanding of the nature and effect of an EPOA, and an understanding that the attorney appointed would assume complete authority over the donor's property and be able to do anything the donor would be able to do with the property.[60]

The EPOA for personal care and welfare form was changed from a 2-page document to a lengthy 15-page format and stricter signing provisions were put in place. Only one person can be appointed for personal care and welfare. The donor must have independent legal advice to ensure he or she understands the implications of what they are doing and

---

[53] Re F (No 3) FC Levin PPPR 031/020/91, 31 January 1992 at 5.
[54] Bell, above n 53, at 4.
[55] At 56.
[56] Law Commission, *Misuse of Enduring Powers of Attorney* (NZLC R71, 2001).
[57] Bell, above n 56, at 36.
[58] PPPR Act, Part 9, amended by the Protection of Personal and Property Rights Amendment Act (2007 No 90).
[59] Bell, above n 58, at 37.
[60] *NJF v MIF* FC FAM-2008-063-759, Family FC Rotorua, 20 December 2010 at [22].

the EPOA must be in a prescribed form (the forms are appended as schedules to the Protection of Property Rights (Enduring Powers of Attorney Forms) Regulations 2008).[61]

A certificate must state that the witness has explained the matters in the prescribed form, their right to suspend or revoke the power of attorney, and, in relation to property, their right to appoint more than one attorney (or a trustee corporation) and their right to stipulate whether, and, if so how, the attorney is to be monitored. Witnesses must be independent, appropriately trained and authorised to certify EPOAs. A solicitor's certificate that confirms the effects and implications of completing an EPOA have been explained to the donor must also be completed.[62] The attorney(s) appointed must have independent legal advice at the time of their appointment.

A Court review of a particular decision made by an attorney precludes reviewing any earlier actions of the attorney (s 103(1).[63] In 2020 there were only 24 s 103 reviews of attorney decision applications and one where leave was granted to review an attorney decision.[64] The Family Court cannot of its own volition instigate a s 103 review under the PPPR Act.[65]

Limitations on EPOAs for personal care and welfare

Section 98 describes when an EPOA is activated and the steps that should be taken by an attorney.[66] An attorney has no authority to activate the EPOA until the donor loses mental capacity; this capacity can fluctuate.[67] The powers given under s 98 can be general powers that include everyday living decisions or they can be subject to specific restrictions. The attorney is directed to act in the donor's best interests and to encourage the donor to make decisions for themselves as much as possible.[68]

A welfare guardian, whether appointed by the Family Court upon loss of capacity (s 12) or by an EPOA, is bound by express limitations: decisions relating to marriage (s18(a)),

---

[61] Bell, above n 60, at 38.
[62] At 38.
[63] At 170.
[64] Ministry of Justice letter (Ref: 90590, number of applications filed under PPPR Act, by application type and year, 2016-2020) (obtained under Official Information Act 1982 Request to A Meates).
[65] PPPR Act, s 103.
[66] Section 98.
[67] Bell, above n 64, at 161.
[68] PPPR Act, s 98A.

adoption (s18(1)(b)), the use of electro-convulsive treatment (s18(1)(d)), brain surgery (s18(1)(e)), or medical experimentation (s18(1)(f)), and consent to standard medical treatment cannot be refused (s18(1)(c)).[69]

For an EPOA for personal care and welfare, an attorney is not able to act in relation to a significant matter unless a medical practitioner, or a court, has certified that the donor is mentally incapable. A significant matter includes a permanent change in the donor's residence, entering residential care, or undergoing a major medical procedure.[70] Where a matter is not deemed to be significant, the attorney only needs to have a reasonable belief that the donor is mentally incapable to act on matters; this is a much lower threshold.

Where incapacity is the result of a long-term condition and the subject person is unlikely to regain capacity, the medical certification first used may remain valid indefinitely in order to prevent unnecessary examinations and charges against the person's property.[71]

2017 amendments

Following a report from the Minister for Senior Citizens in 2016, further minor changes were made to the witnessing requirements and new forms were created for making EPOAs.[72] Further regulations around the use of prescribed forms for EPOAs and information required to be included in a medical practitioner report were also added.[73]

EPOA for property

Provisions for an EPOA in relation to property are also set out in Part 9 of the PPPR Act s 97. Attorneys can be appointed for this role. There is a prescribed form, and the same witnessing provisions apply as for the EPOA for personal care and welfare. This paper does not address specifics relating to a property EPOA.

---

[69] Section 18. S 18 applies to Family Court appointments and EPOAs.

[70] Section 98(6).

[71] Bell, above n 68, at 161.

[72] These changes were introduced in the Statutes Amendment Act 2016 (No 104) and came into force on 16 March 2017.

[73] Regulation 1: amended, on 16 March 2017, by regulation 4(2) of the Protection of Personal and Property Rights (Enduring Powers of Attorney Forms and Prescribed Information) Amendment Regulations 2017 (LI 2017/44).

Standard medical care

A welfare guardian or an attorney cannot refuse their consent to any standard medical treatment or procedure that is intended to save the person's life or to prevent serious damage to that person's health.[74]

While standard medical treatment is not defined, the standard of care normally applied is the treatment that a competent and responsible practitioner would consider clinically appropriate in the circumstances.[75] If the circumstances require emergency treatment, "Consent is not a prerequisite to emergency medical treatment at common law or standard treatment that is intended to save a person's life or to prevent serious damage to her health".[76]

The traditional legal test establishing whether there had been a breach in the standard of care was known as the Bolam test where, if the medical practice was supported by a responsible body of peers, the practitioner had met the required standard of care in law.[77] The main criticism of Bolam was that it allowed the legal standard to be set subjectively by the doctors, by failing to draw a distinction between what is done and what ought to have been done.[78]

In 1998, a House of Lords decision changed this approach.[79] In the Bolitho case it was the court, not the medical profession, that decided whether or not there had been a medical breach.[80] After Bolitho the courts will enquire more closely into the justification of a defendant doctor's practice, based on a logical analysis of why an opinion was formed, as well as a risk analysis against competing options.[81] There are circumstances where it is lawful to cease treatment as to continue would not be good medical practice.[82] The issues raised in both tests highlight the inherent tensions between the medical and legal

---

[74] PPPR Act, s 18(c).

[75] Iris Reuvecamp and John Dawson (eds) *Mental Capacity Law in New Zealand* (Thomson Reuters New Zealand Ltd, Wellington, 2019) at 262.

[76] *KR v MR* case, above n 51, at 858 [56].

[77] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 at 582.

[78] Ash Samanta, Jo Samanta "Legal Standard of care: a shift from the traditional Bolam test" (2003) 3(5) Clinical Medicine 443 at 444.

[79] *Bolitho v City and Hackney HA* [1998] AC 232.

[80] Mulheron, Rachael, "Trumping Bolam: A Critical Legal Analysis of Bolitho's Gloss" (2010) 69(3) Cambridge Law Journal 609 at 609.

[81] Samanta, above n 79, at 445.

[82]Barrett, above n 37, at [30.21.4.(7)].

fields. This tension is pertinent to the discussion around ADs that will be raised further in this paper.

While there is some oversight and monitoring of a welfare guardian appointment from the Family Court, there is little protection for the donor in the operation of an EPOA. It is difficult to know if the 2007 amendments have reduced elder abuse concerns as intended; the writer sees this as unlikely. The writer submits that the signing provisions for an EPOA have become too burdensome and can be difficult to complete outside a legal office. Without a register to activate an EPOA there is little protection afforded to the user.

Advance Directives

What is an advance directive?

An AD has been described more generally as making a choice about treatment and extending that choice to the future.[83]

The first AD law enacted in the USA was California's Natural Death Act 1976, shortly after the Karen Ann Quinlan decision[84] where the New Jersey Supreme Court recognised the constitutional right to refuse medical interventions. Since that time, the rights of self-determination in decisions for future care have been extended to the person who no longer has capacity.[85]

In New Zealand an AD is defined as a written or oral directive by which a person makes a choice about a possible health care procedure; and that is intended to be effective only when the person is no longer competent.[86]

Before the 2007 PPPR Act amendments introduced the term AD, the words 'living will' were used to record a person's wish to refuse medical treatment at a future time. A living will was another term used for an AD, made when a person has a terminal illness.[87] The living will was seen to be an expression of wishes that may or may not be followed by the health practitioners or by family, although the living will had always existed at common law. The term has all but disappeared from the present-day legal vocabulary and been replaced by the term 'advance directive'.

Under the PPPR Act s 99A(2), (3) and (4) the AD is introduced under the heading 'Attorney's duty to consult'.[88] An attorney acting under an EPOA has a duty to consult where practicable (s 99A) and is to have regard to any AD,[89] may follow the advice given

---

[83] AS Kessel and J Meran, "Advance directives in the United Kingdom: legal, ethical, and practical considerations for doctors" (1998) 48(430) British Journal of General Practice 1263 at 1264.

[84] Robert S Olick "Defining Features of Advance Directives in Law and Clinical Practice" (2012) Medical Ethics 232 at 237.

[85] At 233.

[86] In New Zealand the term used is advance directive; United Kingdom and Ireland is advance decision; Australia (Qld) is advance health directive, (SA) is advance care directive. The words will be used interchangeably in this paper.

[87] Ron Paterson in PDG Skegg and Ron Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) 27 at 52.

[88] PPPR Act, ss 99A–99D. These were inserted into the PPPR Act by s14 Protection of Personal and Property Rights Amendment Act 2007 (2007 No 90).

[89] Section 99A(2).

under an AD, and may apply to the court for directions in respect of any advice given under an AD.[90] In summary, the attorney may have regard to the donor's wishes as expressed in an AD if contrary to the limitations imposed on welfare guardians generally under s 18.[91] Other than the s 99A obligations there is no legal framework provided by the legislation, and no further obligations, checks or balances, or guidelines that apply to an AD under the PPPR Act.

The AD was confirmed in the 2017 regulations, with the AD defined as a written or oral directive by which a person makes a choice about a possible future health procedure; and that is intended to be effective only when the person is not competent.

Where does an advance directive operate?

While an AD is usually completed with legal advice, it mainly operates under the HDC Code in accordance with the common law. Common law evolves by developing tests and principles a Judge can apply where there is no statutory test within the applicable legislation.[92] The PPPR Act does not provide these tests and principles for the AD so looks to other international jurisdictions and their case law.[93] The common law applies to any AD even though the person may not be a health consumer under the HDC Code.

For an AD to be legally binding it must be both valid and applicable.[94] The person must have had capacity to make the decision, been free of undue influence, had adequate information to make their decision, and they must have intended their AD to apply to their future circumstances,[95] even if the refusal results in their death.

The capacity test for the AD is established by the common law from the rebuttable presumption that every adult has capacity.[96] The test is a functional approach where a

---

[90] Sections 99A(3) and s 99A(4).

[91] Bell, above n 72, at 164.

[92] Wilmott, Lindy, White, Ben & Mathews, Ben "Law, Autonomy and Advance Directives" (2010) 18(2) Journal of Law and Medicine 366 at 374.

[93] Nuala Kane and Alex Ruck Keene "Capacity Law and the PPPR Act" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 61 at 62.

[94] Ron Paterson "Advance Decisions" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 352 at 357.

[95] Malpas, above n 30, at 286.

[96] *Re T (An Adult: Refusal to Treatment*) [1992] 4 All ER 649; [19992] 3 WLR 782; [1993] Fam 95 at 112.

person has sufficient understanding of the nature, purpose and effects of the proffered treatment.[97]

The person first needs to comprehend and retain information by understanding, in a broad sense, the nature and purpose of the proposed medical treatment and the associated material risks. The person next needs to believe the information they have been given. Then the person must weigh the information presented to them and, after understanding, retaining, and believing the information, must evaluate that information in a reasoned process and consider an outcome.[98] The *Re C* test of capacity has been applied in New Zealand in *Chief Executive of the Department of Corrections v All Means All*.[99] It has also been adopted more recently as part of a threshold test in the Substance Addiction (Compulsory Assessment and Treatment) Act 2017, at s 7 and s 9.[100]

Vague and difficult to interpret wording, or the length of time between writing the AD and when it is to be used, might also influence its validity.[101]

The AD must apply to the present circumstances, which can be problematic if the AD was completed a long time prior. In *HE v A Hospital Trust* an AD was found to be invalid due to the present circumstances of the person being different from those when the AD was made. The case involved a young woman had earlier signed an AD refusing the transfusion of blood or primary blood components while a Jehovah Witness member; she had then revoked her faith and was planning to marry a Muslim man.[102]

The test relating to undue influence is a subjective one, to ensure the decision made is their true choice.[103] In *Re T (Adult Refusal of treatment)* an AD was found to be invalid due to the person misunderstanding the alternatives to a blood transfusion that were available. The refusal had not been contemplated as life threatening so the choice made was not clearly established.[104] In *Kings College NHS Foundation Trust v C* it was held

---

[97] *Re C (Adult Refusal of Treatment)* [1994] 1 WLR 290 at 295.

[98] Jane Goodwin, Nick Laing “Advance Care Planning – Issues For Lawyers” NZLS CLE Ltd September 2019 at 11.

[99] *Chief Executive of the Department of Corrections v Canterbury District Health Board and All Means* All [2014] 3 NZLR 404 at [17].

[100] Goodwin and Laing ACP, above n 100, at 11.

[101] Paterson, above n 96, at 359.

[102] *HE v A Hospital Trust* [2003] EWHC 1017 (Fam), [2003] 2 FLR 408 at 32.

[103] Goodwin and Laing ACP, above n 102, at 13.

[104] *Re T (Adult Refusal of Treatment)* [1992] 4 All ER 649 at 650 [b]-[c].

that Mrs C did intend the directive to apply in the circumstances, saying while many societies would consider the approach was unreasonable, illogical or even immoral, the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weighed heavily in the balance for Mrs C.[105]

The validity of an AD is based on the civil standard of the balance of probabilities.[106] When assessing the validity of an AD the civil standard does not change; depending on the nature of the allegation made, the extent of the evidence required may vary.[107]

An advance directive cannot seek to refuse basic care. While basic care is not defined it does include providing warmth, shelter, actions to keep the person clean and the offer of food and water by mouth.[108]

Although s 99A(4) allows an attorney to apply to the court for directions in respect of any advice given in an AD, there is no clear pathway under the PPPR Act for an AD to be considered. For example, if there is uncertainty as to validity, how and where are decisions being made?

The HDC Code and the advance directive

The HDC Code became law on 1 July 1996 and established a number of rights for people using health and disability services, and obligations and duties of providers to comply with the Code.[109]

The AD is defined in clause 4 of the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 as:

'Advance Directive' means a written or oral directive –

(a) by which a consumer makes a choice about a possible future health care procedure; and

(b) that is intended to be effective only when he or she is not competent

---

[105] *Kings College NHS Foundation Trust v C and V* [2015] EWCOP 80 at [97].

[106] *Hohipa v R* [2015] NZCA 73 at [71].

[107] *Re H* (Minors) [1996] AC 563 at 586.

[108] MCA, s 42(3). Solicitor checklist [13].

[109] The Health & Disability Commissioner "Code of Health and Disability Services Consumers' Rights". <hdc.org.nz/your-rights/about-the-code/>

choice means a decision—
(a) to receive services:
(b) to refuse services:
(c) to withdraw consent to services

And in Right 7(5) of the HDC Code that –

'Every health consumer may use an advance directive in accordance with the common law.'

The HDC Code does not provide any specific guidance or guidelines other than it has to be in accordance with the common law. There is no guidance as to when an AD is legally binding,[110] nor is it codified as in MCA or in Australia, where it is the legislation that confirms the common law right to refuse treatment.[111]

Does an advance directive provide what it promises?

There has been debate and criticism as to whether an AD does provide what it actually promises for people wanting to have continuing autonomy. One view is that an AD provides little value as it is simply not capable of giving a competent person the expected control of future decisions.[112] There are also practical difficulties; an AD could be presented as being a patient's when it is not, as a signature is not always required for an AD to be valid;[113] neither does it need to be witnessed by a health practitioner, solicitor or Justice of the Peace which is very different to the EPOA. In principle, an AD is seen as generally positive and offers a simple and practical way for medical decisions to be made, especially near the end-of-life.[114]

Best interest considerations

Where a person has an AD and there are no reasonable grounds to doubt its validity, the AD must be followed; it is not a best interest assessment.[115] Where a person does not have a valid AD, the focus is then whether it is in the person's best interest to receive treatment, rather than having treatment withheld or withdrawn.[116] This also applies to care for a

---

[110] Paterson, above n 103, at 357.
[111] Wilmott, White and Mathews, above n 94, at 374.
[112] Mark R Tenelli "Pulling the Plug on Living Wills: A Critical Analysis of Advance Directives" (1996) 110 Ethics in Cardiopulmonary Medicine 816 at 821.
[113] Malpas, above n 97, at 287.
[114] At 288.
[115] Paterson, above n 112, at 360.
[116] At 354.

person without capacity, where there is no authorised decision maker under Right 7(4) of the HDC Code.[117]

A study in the United States of 3,011 critically ill adults in seven different intensive care units found that 5.5% of deaths occurred in patients who lacked a surrogate decision-maker and an AD. For 30 out of the 37 patients, the physicians and unit teams were making life-support decisions for the patients, with no formal institutional review or no judicial review in the courts.[118]

The study also found that in two of the institutions intensive care units, 25% of all deaths occurred in incapacitated people without surrogates. It is impossible to know whether the decisions being made would be those that the patient would have made, and because this is uncertain, the process by which decisions are made assumes a greater importance. Most life-support decisions in the study were made by physicians without the input from a hospital review committee or the courts. While the role of the physician was seen as important, as they understand the medical conditions, the study also found that individual physicians made very different choices regarding life support when presented with the same set of facts.[119]

Use of advance directives

In the United States, after 30 years of legislation, approximately 20% of the population have written ADs, although the number has reportedly remained stable over time among the elderly, nursing home patients and people living with HIV/Aids.[120]

In New Zealand there has been little empirical research around ADs[121] so there is no clear figure on their completion rates and actual use. With no specific research figures, an indicative number of 15%[122] may or may not be accurate; in any event it is likely to be low.

---

[117] Angela Ballantyne and Chris Reid “Supported Decision-making” in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity*. *A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 119 at 142.

[118] Douglas B. White et al “Life Support for Patients Without a Surrogate Decision Maker: Who Decides?” (2007) 147(1) Annals of Internal Medicine 34 at 35.

[119] At 38.

[120] Olick, above n 86, at 233.

[121] Paterson, above n 118, at 353.

[122] Wendy Brown “The Uptake of Advance Care Planning by Older Adults in New Zealand” (Master of Arts, Massey University, 2018).

Geriatricians' views

In a study undertaken in 2011 of geriatricians' views of ADs and their use in clinical care in England, it was found that, in principle, they held a positive view of ADs.[123] Where the document conflicted with the geriatricians' clinical opinions it may have a limited influence on decision-making.[124] Geriatricians were most likely to use a document which was prescriptive and specific in terms of treatment to be declined and the clinical situations in which it should apply. For example, the document would clarify invasive treatment, such as intubation or admission to intensive care, or treatment that geriatricians might consider to be 'low level', such as intravenous antibiotics and fluid replacement.[125]

Geriatricians would follow an advance decisions document depending on how it is written,[126] if it clearly fits the clinical scenario, and supports the doctor's own view of best management.[127] To be useful, an advance decision should be seated within wider advance care planning, and include an open discussion of prognosis with patients. The study also found that older people appear to have difficulty influencing decisions relating to their care when they have discussions with doctors.[128]

In the United States a number of preferred practices have emerged. The combination of an AD and the person's health proxy attorney, who can legally make health care decisions, makes them simple to use.[129] The designated person can respond to the patient's current circumstances which avoids having to interpret an AD that may have been written a long time ago and may not have anticipated the patient's current condition and treatment options.[130]

The AD needs to be in writing. It is the law that provides direction as to the formal requirements for an AD around the issue of capacity, when the directive takes effect, the

---

[123] Catherine Jane Bond and Karen Lowton "Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study" (2011) 40(4) Age and Ageing 450 at 455.
[124] At 450.
[125] At 452.
[126] At 454.
[127] At 453.
[128] At 455.
[129] Olick, above n 122, at 232.
[130] At 233.

rights and responsibilities of the attorney, family and health care providers, and the scope and limitations of the decisions.[131]

A suggested form is included in the legislation which, while optional, is often the most recognised form.[132] Other forms are useable as long as they comply with the requisite formalities.[133] There is judicial consensus that a person has the right to refuse all unwanted bodily interventions and draws no distinctions between them.[134] The role of ethics consultation in resolving disagreement, although not required by law, is seen as a further important feature in this area.[135] There are also continuing efforts to ease the legal restrictions to further promote advance care planning.[136]

Māori cultural beliefs around death and dying

Cultural beliefs and practices, religious beliefs and practices, family/whanau beliefs, traditions and individual choice will influence any decisions made around ageing, illness, death and dying.

Te Tiriti o Waitangi recognises the obligations and the relationship between the Crown and Māori as tangata whenua. There are also particular rights and obligations that arise in related legislation.[137]

Māori make up around 16.8% of the population. In terms of the EPOA and AD it has been noted that Māori families rarely appear to have EPOAs and appear to have a cultural reluctance to give the decision-making authority to a son or daughter when families believe that power (mana) within whanau should reside in the older generation (kaumātua and kuia).[138]

---

[131] At 233.

[132] At 234.

[133] The United States also has POLST form, but these are not ADs.

[134] Olick, above n 131, at 236.

[135] At 233.

[136] At 237.

[137] Joanne Baxter "Māori Perspectives" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 153, at 156. Māori also have rights underpinned in the United Nations Declaration on the Rights of Indigenous Peoples 2007 (UNDRIP) United Nations Declaration on the Rights of Indigenous Peoples A/Res/61/295 (opened for signature 29 June 2006, entered into force 13 September 2007).

[138] Mark Fisher and Janet Anderson-Bidois (eds) *This is not my home A collection of perspectives on the provision of aged residential care without consent NZ Human Rights* (New Zealand Human Right Commission, June 2018) at 13.

Over generations Māori have developed cultural healing traditions including rongoa (herbal medicine), mirimiri (massage) to alleviate discomfort, and karakia (prayer).[139] Māori have strong beliefs around death and believe their wairua (spirit) lives on after death. There is a close connection between the living and spiritual worlds in the end-of-life journey where a person's wairua has balance, calm and connection to the whānau to assist on the journey to the spirit world.[140]

The cultural practices around death and dying focus on group orientated values and perspectives that apply to the larger extended family, not just the immediate family.

For elderly Māori who have lost capacity, there is a strong desire to be at home, close to whanau, iwi, hapu and marae so that they are spiritually connected to the land. Karakia is part of protecting the person on his or her way to the next world; waiata (song) supports with pain management and helps the dying person on their journey.[141] Death, dying and bereavement are believed to be central to life and are part of the natural balance of life.[142]

A recent qualitative study involved 241 older Māori (kaumātua), 17 focus groups across Aotearoa and 8 families from 1 region. The research used a Māori methodology approach: 'by Māori, for Māori, with Māori', and led by a Māori world view.[143] The research identified that in capacity assessments for Māori in the early stages of dementia and cognitive impairment, the language used can influence and cause a variation in the results of an assessment.[144]

This study acknowledged previous models used which identified similar themes that contribute to Māori health including the core components: the mind (hinengaro), spirit (wairua), body (tinana) and family (whānau).[145] What the study did highlight were two

---

[139] *Ageing and Indigenous Health in Aotearoa New Zealand Position Statement 24* (Australasian & New Zealand Society for Geriatric Medicine, 2020).
[140] John Oetzel, and others "Managing Communication Tensions and Challenges During the End-of-Life Journey: Perspectives of Māori Kaumātua and Their Whānau" (2015) 30(4) Health Communications 350 at 351.
[141] At 354
[142] At 351.
[143] Oliver Menzies and others "He Tūhonoga Whaiaro: A Kaupapa Māori Approach to Mate Wareware (Dementia) and Cognitive Assessment of Older Māori" (2021) Journal of Applied Gerontology 1 at 2.
[144] At 1.
[145] At 6.

additional important themes relevant to the health of older Māori with dementia. The themes are important as they can assist and guide those making capacity assessments: connection (tūhononga) and self (whaiaro).[146] Tūhononga reflects the importance of connection and the collective and is integral to relationships for place (wāhi), ancestors (tipūna), family (whānau) and social connection (whanaungatanga).[147] Whaiaro focuses on the person, within the collective of the family, the spirit (wairua), the mind (hinengaro), identity and role (tuakiri) and the body (tiana).[148]

An understanding of tūhononga and whaiaro for elderly Māori with cognitive impairment can assist in sensitive and respectful conversations[149] could include supported decision making with whanau, with recognition of the Hui Process to support the communication.[150]

---

[146] At 7.
[147] At 3.
[148] At 5.
[149] *Ageing and Indigenous Health in Aotearoa New Zealand Position Statement 16* (Australasian & New Zealand Society for Geriatric Medicine, 2020).
[150] Cameron Lacey and others “The Hui Process: a framework to enhance the doctor-patient relationship with Māori” (2011) 124(1347) The New Zealand Medical Journal 72 at 72.

ACP and the advance directive

The ACP concept has developed internationally from the late 1970s[151] and in NZ from the 2000s.[152] ACP is described as being a process of thinking, talking and planning for a person's future healthcare and end-of-life care by identifying what is important for them in relation to this care.[153] It is a way of providing care that is respectful of, and responsive to, patient preferences, their needs and values, and ensuring patient values guide all clinical decisions.[154] An effective Advanced Care Plan [AC Plan] encourages conversation, helps a person achieve a sense of control, engages others and provides reassurance to the person.[155] These conversations and discussions can involve the person and their family/whānau, health care professionals and, in some cases, the person's lawyer.[156] The can happen over time and cover the values, beliefs, concerns, hopes, goals, priorities and wishes for care during the final days; practical issues such as funeral arrangements and the location of important documents.[157]

While there is an inherent right for people to refuse treatment under New Zealand legislation, it is very difficult to identify a process to do so. The AD was codified in the PPPR Act legislation in 2007 but operates under a code set up for patient rights and is largely included within the structure of ACP.

The National Advance Care Planning Cooperative was formed in June 2010 by clinicians and health care providers, with Ministry of Health [MoH], support, with a vision for everyone in New Zealand to have access to comprehensive, structured and effective advance care planning. Its goal was to develop a common understanding, framework and direction for ACP in all areas and for all communities. The four key priorities set were consistent language and documentation, public engagement and education, staff training and communication, and cultural appropriateness.[158]

---

[151] Barry Snow "ACP Deployment: The New Zealand Experience" (2015) 5(2) BMJ Supportive & Palliative Care A1 at A1.

[152] Jane Goodwin and others "Achievements and challenges during the development of an advance care planning programme" (2021) Australas J Ageing 1 at 2.

[153] Henricus Berend Speelberg and others "An evaluation of the contents of advance care plans and their use in patients admitted to a public hospital" (2020) 133(1526) NZMJ 55 at 55.

[154] William Silvester and others "Quality of advance care planning policy and practice in residential aged care facilities in Australia" (2013) 3 BMJ Supportive & Palliative Care 349 at 349.

[155] *Advance Care Planning A Guide for the New Zealand Workforce* (Ministry of Health, August 2011) at 7.

[156] Jane Goodwin and Nick Laing "End-of-life Choice Act" (NZLS CLE Webinar, August 2021) at 19.

[157] At 21.

[158] MOH, above n 157, 29.

The national ACP round table governance group included NGOs, Ministry of Health, education providers, networks, District Health Boards, residential care providers, colleges and consumers. The mission statement for the cooperative is to

> *'... work with government and non-governmental agencies, to advance its aims and objectives within the current legal and ethical context in a manner that is coordinated, evidence-based and outcomes focused'.*[159]

The advance directive within advance care planning

The AD has statutory legitimacy in s 99A, PPPR Act, the AD operates under the HDC Code; the principles that apply are found in the common law. While the HDC Code defines a user as a health consumer or a disability consumer,[160] under the common law it can apply to everyone and an AD would be followed if the common law legal criteria are met. ACP is about ensuring that the treatment and care a person receives is aligned to their personal preferences, values and beliefs; this in turn assists with the care received towards the end-of-life, and also recognises the limits of modern medicine.[161]

ACP is developing further internationally around the principles expressed in the Convention on the Rights of Persons with Disabilities [CRPD] which promotes supported decision-making, values and preferences for people with disabilities and people without capacity. In New Zealand an AC Plan is not in itself a legal document, but rather a recorded statement of wishes and preferences usually around the person's end-of-life care. An effective AC Plan does not require an AD to be completed. In a recent New Zealand Law Society continuing education seminar (ACP – Issues for Lawyers) the AD was only mentioned within the larger concept of ACP conversations. In a diagram, the AD was represented by the smallest circle surrounded by an ACP circle inside a larger conversations circle. [162] The use of an AD other than within ACP was not addressed, and in practice there appears to be much confusion around the form of the AD; this is not assisted by a lack of direction and guidance in legislation.

---

[159] At 29.

[160] Consumer means a health consumer or a disability services consumer; and, for the purposes of rights 5, 6, 7(1), 7(7) to 7(10), and 10, includes a person entitled to give consent on behalf of that consumer.

[161] MOH, above n 161, at 1.

[162] Goodwin and Laing EoL, above n 159, at 20.

It is acknowledged that where a documented AD or an AC Plan, completed after well-informed discussion involving both the individual and the health care professional, it is likely to meet the criteria for validity. The MoH view is that an unrecorded oral directive or plan or an AD drafted either by the individual on their own, or as a legal document in isolation from health care professionals, is less likely to meet those criteria.[163] This view appears not to support the importance of completing an AD by people outside the health system. The writer argues that it is problematic that there is often no legal involvement in health discussions.

How is the ACP operating in New Zealand?

ACP is operating and accepted nationally. In 2013 ACP was introduced into Canterbury[164] when a working group, The Canterbury Initiative, was formed which included general practitioners, public hospital specialists and nursing representatives.[165]

The group identified four key areas as crucial for a successful implementation of ACP: credibility, a consistent and recognisable format; quality management and digital sharing.[166] Two facilitators were appointed to develop a programme with a specific group to implement the programme; there was a subsidy to fund the increased general practice work, a digital sharing platform for completed AC Plans and the programme was well supported from management.[167]

The programme was monitored through research which identified a number of specific findings. The research included a review of 3,238 people, median age 79 years,[168] who had finalised an AC Plan between December 2013 and December 2019. Many of these people were severely ill at the time and required high-level care; the majority died within a year of completing their AC Plan. For 59 out of 60 cases where the patient was assessed as incompetent and unable to make decisions during the hospital admission, the plan was followed.[169] The programme also highlighted that people in minority ethnic populations,

---

[163] MOH, above n 163, at 17.
[164] Goodwin and others, above n 154, at 1.
[165] At 2.
[166] At 2.
[167] At 2.
[168] At 4.
[169] At 5.

including Māori, or those in a deprived socio-economic quintile, were less likely to have an ACP and were less likely to have made plans.[170]

Another study at the Canterbury DHB examined the influence of age and comorbidities on the consistency between the wishes and actual care received during a hospital admission. That study size was 149 with a median age of 78 years.[171] The findings included that a person's age had a measurable influence on their care choices, with older people tending to want only treatment that maintained their comfort and dignity.[172]

Some of the factors that may influence a person's decision to make an ACP are their prognosis, gender, age, cultural and ethnic background, religion and education. Those diagnosed with a more severe medical condition had a greater tendency to want their end-of-life care decisions to be made by healthcare professionals, in consultation with family members and friends.[173]

> "*The findings support the usefulness of ACPs in that they provide the opportunity for patient choice and self-determination and encourage the wishes of hospitalized patients to be recognized and used to guide care.*"[174]

ACP can reduce hospitalisation rates and increase hospice and palliative care, although the care is not always consistent with a person's preferences. In the above study 48% of people died in their preferred place, 36% died in a non-preferred place and 16% had no preference stated.[175]

Other countries

The international approaches have a different structure in place for ACP. The jurisdictions mentioned below all have a comprehensive statutory framework and guidelines that support legislation around lasting powers of attorney [LPA], there is a definition of both capacity and ADs. ACP operates outside the legislation but encompasses EPOA and ADs.

---

[170] At 1.
[171] Speelberg, above n 155, at 58.
[172] At 63.
[173] At 63.
[174] At 64.
[175] At 63.

Australia

In Australia the advance health directive [AHD] is part of ACP. While there has generally been low AHD (and ACP) uptake it is gaining more prominence as an important component of good end-of-life care.[176] The issues around the slow uptake include lack of awareness, general reluctance to discuss end-of-life issues, and a lack of health professionals' involvement.

England and Wales

While the term ACP is not used in the MCA, the concept is clearly included. The Act reinforces the common law principle, based on the right of any individual to consent to or refuse treatment;[177] the process seeks to clarify a person's understanding of illness and treatment, as well as identifying their beliefs, values and goals before considering future wishes.[178]

The MCA allows for three possible outcomes of ACP, to take effect when a person loses capacity. First, a person can make an advance statement of wishes for future care, based on a consideration of the person's best interests; this statement is not legally binding, but it should be referred to. Secondly, there is the advance decision to refuse treatment which has the same effect as a refusal by a patient with capacity. It is a legally binding document and must be valid and applicable. Thirdly, there is an LPA for health and welfare decisions. An attorney is appointed to make decisions on best interest criteria where a person lacks capacity. The LPA must be registered to be used. The health care professional is required to consult with the attorney where the person lacks capacity. The legally binding nature of decisions made as part of an ACP refers only to advance refusals.[179]

---

[176] Joel J Rhee, Nicholas A Zwar and Lynn A Kemp "Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews" (2021) 36(1) Australian Health Review 98 at 98.

[177] Benedict Hayhoe and Amanda Howe "Advance Care Planning under the Mental Capacity Act 2005 in Primary Care" (2011) 61 British Journal of General Practice at 537 at 589.

[178] At 537.

[179] At 539.

ACP has been well supported[180] by healthcare professionals and patients[181] and there are national guidelines recommending ACPs as best practice in both dementia and palliative care.[182]

While there are national policy initiatives that support the use of an ACP, there has been considerable reserve around the actual value of an ACP in practice.[183] In a study undertaken in the North East of England[184] while confirming that for older people, including those with cognitive impairment, having an ACP can reduce hospitalisations and increase palliative interventions,[185] the results raised a number of concerns about the ability of an ACP to actually deliver on the patient choices made.[186]

The concerns included a view that ACP is duplicating current practice for patients with dementia. There was doubt that an appropriate plan could be completed for the dementia patient due to their inability to engage in planning, often preferring their health decisions to be made by the medical team. Another concern was around the legal status of an AC Plan for ambulance staff in an emergency and the idea that a one size fits all approach is not necessarily effective.[187]

The law and ACP in New Zealand

MOH Advance Care Planning: A guide for the New Zealand Health Care Workforce has operated since August 2011. The guide does state that in the New Zealand context it is likely, but as yet untested, that a written advance care plan would constitute an AD for legal purposes.[188] The writer considers this assumption to be very uncertain, due to our current lack of protective legislation.

The relevant legal framework for ACP includes international law and conventions, domestic and the common law. This includes the Declaration of Human Rights 1989, the

---

[180] Louise Robinson and others “A qualitative study: Professionals’ experiences of advance care planning in dementia and palliative care, ‘a good idea in theory but…” (2013) 27(5) Palliative Medicine 401 at 407.

[181] Hayhoe and Howe, above n 179, at 538.

[182] *National Dementia Strategy Living well with dementia: a national dementia strategy 2009* (Department of Health, UK).

[183] Robinson above n 182, at 407.

[184] At 401.

[185] At 402.

[186] At 403.

[187] At 406.

[188] Ministry of Health above n 165, at 17.

International Covenant on Civil and Political Rights 1966, and the International Covenant on Economic, Social and Cultural Rights 1966, the Human Rights Act 1993, New Zealand Bill of Rights Act 1990 [NZBORA], the HDC Code, and the CRPD.[189]

ACP strengths

ACP has many strengths and practical applications for our increasing and ageing population and provides a relatively flexible procedure around end-of-life care. The Canterbury experience shows an organised system with procedures in place supported by ACP facilitators, a training programme and education, with a health pathway connecting the medical profession and patients, together with access to a digital platform for documentation.

The Canterbury research also supports international research that older people are more likely than younger people to engage, and be open to being engaged, in conversations around health choices and their end-of-life care. The wider vision for ACP is that every person will know about ACP from a relatively early age and engage in the process during the course of their life, rather than just being used as a document for end-of-life care.[190]

MOH published ACP guidelines for the New Zealand health workforce in 2011; the concept is well supported within the health sector.

Questions to be asked for an ACP

In a 2014 MOH report concerns were raised around the lack of clarity of the law as it relates to AC Plans, ADs and EPOA. These included: whether an AC Plan would constitute an AD for legal purposes; the lack of case law testing actions of a health professional when they make a decision in the face of an AD on behalf of a person who lacks capacity; lack of definitions for an AC Plan, AD and EPOA;[191] and a lack of a centralised electronic system to securely store advance care plans.

Other questions relating to ACP have been raised such as: reviewing best interest decisions made for end-of-life care for a patient without capacity,[192] the involvement of

---

[189] Jane Goodwin and Nick Laing ACP, above n 102, at 5.
[190] Comment by Dr Matthew Croucher.
[191] MOH Report (2014) at 134.
[192] White, above n 120, at 34.

the medical ethics committee,[193] the process for a judicial or HDC Code review, the protection of patient rights, and compliance with international conventions.

The concerns raised by the MOH and others remain under the current law, with a lack of guidelines and limited judicial and HDC oversight for the very people that these systems are supposed to protect, in particular people without capacity.

Does the concept of ACP fit with CRPD?

New Zealand ratified the CRPD in 2008,[194] but does New Zealand comply? Under the CRPD people with disabilities, including those with impaired capacity, have the same rights as everyone else.[195] This includes respect for human dignity and individual autonomy.

The CRPD sets out a number of principles that include freedom for people with disability to make their own choices[196] with free and informed consent, have the right to liberty and security,[197]to be free from exploitation, violence and abuse.[198] There can be no discrimination on the grounds of disability.

There has been a paradigm shift in capacity law, with the focus moving from whether a person has the mental capacity to exercise their legal capacity to whether they have the necessary support to do so.[199] The person is recognised as an individual before the law[200] with the same rights as everyone else, with appropriate supports in place,[201] and access to the legal system if and when required.[202] The CRPD implies that the person's wishes and preferences would be binding, or that every attempt would be made to include those wishes and preferences in decision-making.[203]

---

[193] At 35.

[194] The United Nations Convention on the Rights of Persons with Disabilities A/RES/61/106 (opened for signature 30 March 2007, entered into force 03 May 2008.

[195] A Douglass, G Young and J McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Wellington Press 2020) at 24.

[196] CRPD, art 3.

[197] CRPD, art 14.

[198] CRPD, art 15.

[199] Michael Bach and Lana Kerzner *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Commission of Ontario, October 2010) at 16.

[200] Ballantyne and Reid, above n 119, at 122.

[201] Douglass, Young and McMillan, above n 197, at 25.

[202] Ballantyne and Reid, above n 202, at 122.

[203] Douglass, Young and McMillan, above n 203, at 25.

The United Nations committee has expressed the view that under the CPRD there can no longer be substituted decision-making, nor can there be a best interest decision-making framework. Further, the Committee considers that a person is denied the core human right to be recognised under the law if they were to fail a capacity test.[204] Not all of the United Nations' views have been adopted internationally, in particular in relation to the best interest provisions.[205]

Within the positive obligations inherent in the CRPD there are specific aims that are relevant to New Zealand's clinical and legal practice under the current legal framework, such as supported decision-making and recognition of tikanga Māori.[206]

---

[204] Ballantyne and Reid, above n 204, at 120.
[205] The MCA and MCANI have retained best interests in their legislation.
[206] Douglass, Young and McMillan, above n 205, at 25.

Capacity

The importance of the determination of capacity

The kind of life people will lead as they age will be greatly impacted whether or not they are assessed to have or to lack capacity.

With capacity, older people are able to express their views unreservedly and will continue to make decisions for themselves about their personal care and welfare, their property and financial decisions, and how they wish to live their lives.[207]

However, with a determination of a loss of capacity, a person will lose the ability to make decisions for themselves for personal care and welfare, financial decisions, health decisions, and if they do not have their EPOA and an AD in place, those decisions are likely to be made for them by others. Such a determination has been described as potentially being both invasive and draconian;[208] the restrictions on a person's freedom of movement and general liberty come at a huge personal cost.[209]

This section sets out the capacity tests and environs that determine how capacity is assessed in New Zealand, the United Kingdom, Northern Ireland and Australia and identifies the differences in approach within these jurisdictions. Issues that are considered include medico-legal decisions that may be required to be determined, and what may be a way forward in this area and the implications for a person who no longer has capacity.

What is capacity?

Capacity is a legal decision informed by medical and other evidence.[210] In legal proceedings, it is the judge who will make the decision as to capacity, often relying heavily on the medical evidence presented. In practice, this reliance on the medical experts in determining capacity[211] has been questioned by some and will be commented on later in this paper.

---

[207] Bell, above n 93, at 50.

[208] *PC and NC v City of York Council* [2013] EWCA Civ 478 per Hedley J at [13].

[209] Mark Fisher "Liberty and Placement in Care" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 193 at 194.

[210] *McFadzean v Moleta* [2013] NZHC 1601 per Collins J at [7].

[211] Douglass, Young and McMillan, above n 208, at 409.

New Zealand's capacity legislation

In New Zealand the two main pieces of legislation for capacity are the PPPR Act and the HDC Code.[212] The term 'capacity' is not defined in either piece of legislation; neither is there a definition of 'lack of capacity' in the PPPR Act.[213] The HDC Code does not codify a legal test for capacity to consent to treatment or health care;[214] this test is found in the common law.[215]

PPPR Act and capacity

The PPPR Act states it is 'An Act for the protection and promotion of the personal and property rights of persons who are not fully able to manage their own affairs,[216] and seeks to protect and promote the rights of this vulnerable group of people[217] in respect of financial, care and welfare decisions.[218] It also seeks to balance a person's right of autonomy with a need for protection.[219]

The PPPR Act provides the legal structure to assess capacity and codifies the common law, taking a functional approach.[220] The focus is then on the process of decision-making and the person's abilities, rather than the possible outcome of the decisions made.[221]

The PPPR Act was introduced in 1998 with amendments made in 2007 and additional minor amendments in 2017. The Act is generally seen as being difficult to navigate and use.[222] There are six statutory capacity tests that can be applied in determining capacity.[223] It is necessary to first identify the decision that needs to be made so that the relevant capacity test and legal threshold can be correctly applied.[224] Three of the capacity tests set the threshold for intervention by the Court: personal orders (s 10), the appointment of

---

[212] Kane and Keene, above n 95, at 61.
[213] PPPR Act, s 2.
[214] Alex Ruck Keene "Capacity and Health Care" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 94, at 102.
[215] At 103.
[216] PPPR Act, Long Title.
[217] Kane and Keene, above n 214, at 65.
[218] Alison Douglass "Rethinking necessity and best interests in New Zealand mental capacity law" (2018) 18(1) Medical Law International 3 at 3.
[219] At 7.
[220] Douglass, Young and McMillan, above n 213, at 391.
[221] Kane and Keene, above n 219, at 74.
[222] Douglass, Young and McMillan, above n 222, at 390.
[223] Jane Casey and Andrew Steele "In Short Capacity – Practical Insights" (New Zealand Law Society Continuing Legal Education, September 2021) at 12.
[224] Kane and Keene, above n 223, at 74.

a welfare guardian (s 12) and the appointment of a property manager (s 31). Two of the tests set the threshold for activating an EPOA for personal care and welfare, and for property; one test forms part of the witnessing requirements for the making or revoking of an EPOA.[225]

Adding to the complexity of the PPPR Act, are the interchangeable use of the words 'capacity' and 'competence'. Competence is the term used in a clinical context and capacity is the legal term used.[226] In *Re Tony*, Judge Inglis QC said of the use of the word competence and capacity:

> "*…it does not matter greatly whether the disability from which the person concerned is said to suffer is described in terms of 'capacity' or 'competence', for the essential issue in terms of the act is the extent to which his power to function is impaired in particular respects. That must necessarily be a matter of degree, to be assessed and determined in each particular instance.*"[227]

Each of the six capacity tests has its own nuances.

The first test is expressed in the alternative with an either/or option for s 6 which applies when a person (who must be a New Zealand resident) either wholly or partly lacks the capacity to understand the nature and foresee the consequences of personal care and welfare decisions, or has the capacity to understand the nature, and to foresee the consequences, of such, but wholly lacks the capacity to communicate those decisions.[228] This test applies for the making of a s 10 personal order. The differences in the sections are subtle, but are very relevant in a clinical assessment.[229]

The second test applies to an application to the Family Court for the appointment of a welfare guardian under PPPR Act s 12. This is a two-limb test and applies a more rigid threshold.[230] The Court must be satisfied that the person wholly lacks capacity to make or communicate decisions about their personal care and welfare and that the appointment

---

[225] At 76.
[226] Douglass, Young and McMillan, above n 224, at 456.
[227] *Re Tony*, above n 43, at 614.
[228] PPPR Act, ss 6(1)(a) and (b).
[229] Casey and Steele, above n 225, at 13.
[230] Kane and Keene, above n 227, at 78.

of a welfare guardian is the only satisfactory way forward.[231] The use of the word ‘wholly’ can make a significant difference in each specific case. A welfare guardian should not be appointed if there is a satisfactory alternative to ensure appropriate welfare decisions can be made.[232]

The third test applies for an application to the Family Court for the appointment of a property manager under PPPR Act s 31, with the Court’s jurisdiction set out in s 25. For an appointment of a property manager partial incompetence will be sufficient. In deciding whether to exercise its jurisdiction a Court may have regard to the degree to which the person is subject to, or is liable to be subjected to, undue influence on the management of their property affairs.

The fourth test relates to the appointment of an EPOA for property and applies where a person is not wholly competent to manage his or her own affairs in relation to his or her property.[233] The words ‘not wholly competent’ for the EPOA for property is a higher threshold than for the Court appointed property manager under PPPR Act s25, where the words ‘lacks wholly or partly the competence’ are applied.[234]

The fifth test relates to the appointment of an EPOA for personal care and welfare in s 94(2) of the act. This test differs from the test for the Court appointed welfare guardian under s 12 where the person must wholly lack the capacity to make or to communicate decisions relating to their welfare. The test provides four alternatives when deciding whether a person lacks capacity. The person lacks capacity where they are unable to make a decision about a matter relating to their personal care and welfare, or understand the nature of decisions about matters relating to their personal care and welfare, or to foresee the consequences of decisions about matters relating to their personal care and welfare or of any failure to make such decisions, or communicate decisions about those matters.[235] In practice, this test requires special consideration when instructing a clinician carrying out a capacity assessment.[236]

---

[231] PPPR Act, ss 12(2)(a) and (b).
[232] Casey and Steele, above n 231, at 14.
[233] PPPR Act, s 94(1).
[234] Casey and Steele, above n 234, at 16.
[235] PPPR Act, ss 94(2)(a) and (b).
[236] Casey and Steele, above n 236, at 16.

The sixth test applies to witnessing. The witness must certify that they believe, on reasonable grounds, that the donor understands the nature of the instrument, understands the potential risk and consequences, is not acting under undue pressure or duress, and that the witness has no reason to suspect the person was or may have been mentally incapable at the time the person signed the instrument.[237] While the certification expects a lot from the witness, the standard is on reasonable grounds.[238] An assessment by a health professional may be required under certain circumstances. In *Re Tony*, the Court determined that:

> *…all that was required of [the donor] when he executed his enduring power of attorney was capacity to understand the broad essentials of an enduring power of attorney, including the understanding that he was placing his property in safe hands.*[239]

In s 94(3) the test for incapacity for an EPOA does not affect any rule of law relating to capacity to give or to revoke a power of attorney preserving the common law to determine such capacity.[240]

While these capacity tests apply for orders made by the Family Court and for EPOAs, the functional test for capacity from the MCA has been accepted in New Zealand case law[241] and is based on a person's inability to understand, retain, use or weigh, or communicate the relevant information in relation to a specific decision.[242]

The New Zealand Court of Appeal has applied the MCA test and case law to the Court rules for the appointment of a litigation guardian.[243] It has also been used in the Family Court as a checklist for assessing the best interests of a person under the PPPR Act.[244]

---

[237] PPPR Act, ss 94A(7)(ab)(i) - (iii) and s 94A(7)(b).

[238] PPPR Act, s 94A(7)(c). The witness must be independent of the attorney and is satisfied that there is no more than a negligible risk of a conflict of interest arising.

[239] *Re Tony*, above n 230, at 609.
Re Tony must be read subject to s 94A and in particular s (7)(ab) which came in to force on 16 March 2017.

[240] Casey and Steele, above n 238, at 17.

[241] Chief Executive of the Department of Corrections v Canterbury District Health Board and All Means All [2014] NZHC 1433.

[242] Douglass, Young and McMillan, above n 228, at 468.

[243] *Corbett v Patterson* [2014] NZCA 274; [2014] 3 NZLR 41 Randerson J upholding the High Court decision: [2011] 3 NZLR 41 Priestley J.

[244] *CA v EA* [2017] NZFC 7045 Judge Walsh at [29]-[134] and [138].

The MCA capacity test was also applied by medical experts and adopted in the High Court of New Zealand.[245] The High Court still retains its inherent ‘parens patriae’ jurisdiction where the PPPR Act does not cover a specific legal situation[246] and can be used for people who are not competent to manage their affairs (s114 PPPR Act).[247]

For an advance directive, other than the mention in s 99A PPPR Act, there is no specified capacity test in the PPPR Act legislation. The capacity test for an advance directive is found in the common law,[248] where the person must be able to understand the nature, purpose and effects of the proposed treatment; weigh up the options; weigh up the risks and benefits, including the likelihood of success and any alternative forms of treatment; appreciate the possible consequences of receiving, or not receiving, the proposed treatment; and communicate their decision.[249]

Capacity and the HDC Code

While the PPPR Act provides the statutory framework for capacity tests, an AD in New Zealand operates under the HDC Code, and is determined by the common law.[250] There is no definition or legal test for capacity to consent to treatment or health care in the HDC Code; the test applied is the common law test.[251]

The capacity test in the United Kingdom

In the United Kingdom it is the MCA that applies. The MCA received Royal Assent on 7 April 2005 and came into force during 2007. The MCA provides a comprehensive statutory framework for people in England and Wales who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they lack capacity in the future.[252] It developed when it was questioned whether the doctrine of necessity provided the necessary framework for the delivery of medical treatment to those unable to consent. MCA 2005, Section 5, essentially codifies the

---

[245] *Chief Executive of the Department of Corrections v Canterbury District Health Board and All Means All* [2014] NZHC 1433 at [17].

[246] Kane and Keene, above n 232, at 73.

[247] At 74. (The Substance Addiction (Compulsory Assessment and Treatment) Act 2017 legislation ss7 and 9 has used the test.)

[248] Keene, above n 217, at 118.

[249] At 103.

[250] At 118.

[251] At 102.

[252] Mental Capacity Act 2005 Code of Practice (Department of Constitutional Affairs, 2007) at 1.

common law doctrine of necessity.[253] It sets out how decisions should be made by and on behalf of adults whose capacity is in doubt.

The MCA 2005 has codified the common law and applies a single capacity test that determines a person's functional ability.[254] The MCA is supported by comprehensive guidelines which provide guidance, information and examples that demonstrate how the MCA works.

The MCA is based on five governing principles, three relating to capacity and two to best interests. The three principles that apply to capacity are: the assumption a person has capacity unless it is established there is a lack of capacity (principle 1); that all practicable steps are taken to help before a person is treated as unable to make a decision (principle 2); an unwise decision does not mean a person is unable to make a decision (principle 3). The two best interest principles are: decisions for a person who has lost capacity are to be made in their best interests (principle 4); and regard must be had of the person's rights and freedom of action in decisions made (principle 5).[255]

The MCA has a clear definition for a person who lacks capacity:

> '*For the purposes of the Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'* (MCA, s 2(1))

This is a functional test and the person's inability to make a decision must have a causal link to the diagnostic test then applied for 'an impairment of, or a disturbance in the functioning of, the mind or the brain' in (MCA, s3). The functional test in MCA s 2 is always applied first.[256]

---

[253] Keene, A, and others "Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection" (2019) 62 International Journal of Law and Psychiatry 56 at 58.

[254] At 56.

[255] At 58.

[256] At 59.

The MCA also includes legislation for LPAs[257] and for advance decisions. [258] The Act recognises the binding nature of an advance decision.[259] It sets out what an advance decision to refuse treatment means in general (MCA s24), what is required for a valid and applicable advance decision (MCA s25), and the effect of an advance decision. (MCA s26)

The Code sets out what is meant by an advance decision and provides guidance on making, updating and cancelling advance decisions, how to check whether an advance decision exists, how to check that an advance decision is valid and that it applies to current circumstances, the responsibilities of healthcare professionals when an advance decision exists, and how to handle disagreements about advance decisions.[260] Practical scenarios are set out to demonstrate how the MCA is to be used; it is comprehensive and very useable.[261]

The capacity test in Northern Ireland

The MCANI 2016 mirrors some components of the MCA. However, the mandatory prerequisites for any interference with a person's autonomy without their consent are the impairment of decision-making capacity and a person's best interests.[262] This applies across all medical specialties.[263]

This legislation is more recent than the MCA and was developed after a major review of the mental health and learning disability services in Northern Ireland (the Bamford report). The MCANI is also supported by regulations and a comprehensive Code of Practice. The Bamford review found that the legislation at that time did not comply with the principles of autonomy, justice, benefit and least harm.[264] The review found that new legislation should include a single comprehensive legislative framework around mental

---

[257] MCA, ss 9-23.
[258] MCA, ss 24-26.
[259] Sylvia Bell and Warren Brookbanks "Decision-making and the Protection of Personal and Property Rights Act 1988" in Kate Diesfield, Ian McIntosh (eds) *Elder Law in New Zealand* (Thomson Reuters New Zealand Limited, Wellington, 2014) 88 at 103.
[260] MCA Code of Practice, above n 254, at 158- 172.
[261] At 172.
[262] Gerard Lynch, Catherine Taggart and Philip Campbell "Mental Capacity Act (Northern Ireland) 2016" (2017) 41(6) BJPsych Bulletin 353 at 354.
[263] At 353.
[264] At 354.

health legislation and capacity, with agreed principles which would apply to all healthcare decisions.[265]

The MCANI uses both a diagnostic test and a functional test, to reach a decision about a person's decision-making capacity.[266] For the diagnostic test the reason a person is unable to make a decision must be because of an impairment or disturbance in the functioning of the mind or brain. The functional test is about a particular ability at a particular time; this test is not directly linked to diagnosis or disability. The person is unable to understand the information that is relevant to the decision, to retain the information long enough to make the decision, to appreciate the relevance of that information and use and weigh the information as part of the process of making that decision, and communicate the decision.[267]

With a presumption that a person has capacity, there must be no unjustified assumptions made of that person based on age, appearance or condition, there must be respect for a person's decisions, even if considered to be unwise, and the person must be given all practical help and support. A causal link must be established between the two tests, with the person unable to make a decision because of impairment or disturbance in the brain or mind.[268]

The MCANI test for capacity includes the word 'appreciation' in clause 4(1)(c) which has been seen to expand the concept of capacity away from the purely cognitive terms to a concept of capacity that can be affected by emotions, delusion and lack of insight.[269] The words used in the MCANI include the need to both 'use and weigh' information as opposed the MCA wording in the alternative of 'use or weigh'.[270]

The MCANI has legislated for robust LPAs which must be registered with the Office of the Public Guardian before being activated; this extends to both health and welfare decisions. Where the attorney reasonably believes the person lacks capacity they must act in the person's best interest; an advance decision to refuse treatment must be complied

---

[265] At 354. This includes welfare and financial needs.
[266] At 355.
[267] At 356.
[268] At 356.
[269] At 360.
[270] MCA, s 3(1)(c).

with if valid and applicable under common law. An effective advance decision to refuse treatment for a mental disorder cannot be overridden if made when the person had capacity.[271]

The capacity test in Queensland

In Australia the legislation and regulations around capacity law varies in the format and complexity depending on the state or territory,[272] although a degree of uniformity is slowly being achieved.[273] In light of the ageing population and the increasing need for capacity assessments new legal standards and processes have been developed to manage competency-related issues that can be used in both legal and health structures.[274]

In Queensland it is the Power of Attorney Act 1998 (Qld) [PAA] and Guardianship and Administration Act 2000 [GAA] that is the relevant legislation for capacity. Queensland's legislation is now supported by the Capacity Assessment Guidelines 2020 which provide a guide to understanding capacity, capacity assessment and the legal test of capacity under the Queensland guardianship legislation.[275] The guidelines are comprehensive, clear and easy to read and follow.

The general rule is that a person with legal capacity may execute a power of attorney. Each State and Territory in Australia permits the execution of both general and enduring powers of attorney. A general power of attorney will terminate on the loss of capacity.[276] To make an EPOA in Queensland the person is required to understand the nature and effect of the EPOA.

Under the PAA there are two legal tests for capacity, depending on the type of decision to be made. The first test is applied for decisions about personal, health or financial matters. The person must be capable of understanding the nature and effect of decisions about the matter, freely and voluntarily making decisions about the matter and

---

[271] Lynch, above n 271, at 357.

[272] Berna Collier, Chris Coyne, Karen Sullivan Mental Capacity, Powers of Attorney and Advance Health Directives (The Federation Press 2005) at 1.

[273] At 26.

[274] At 158.

[275] Queensland Government "Queensland Capacity Assessment Guidelines 2020 A guide to understanding capacity, capacity assessment and the legal tests of capacity under Queensland guardianship legislation" (2020).

[276] Collier, Coyne and Sullivan, above n 276, at 6.

communicating the decision in some way. Each of the criteria must be met to have the capacity to the make the decision. There is an explanation, examples and a capacity assessment checklist for this test.[277]

The second test for capacity applies to the making of an EPOA; this is a two-stage test.[278] The person must be capable of making an EPOA freely and voluntarily and understand the nature and effect of the EPOA.[279] A checklist of the requirements that must be fulfilled for the second limb of the test is set out in s 41.

For the AHD, there is also a two-stage test, but is the reverse required for an EPOA. The person must understand the nature and effect of the AHD and, secondly, be capable of making the AHD freely and voluntarily.[280] There is a further clause that stipulates that the person has the capacity to make an AHD if that person has the necessary capacity to make an EPOA giving the same power.[281] An attorney appointed under an AHD in Queensland may not make decisions concerning the special health care of the person without capacity; special health care is defined in the Act.[282]

Why is capacity so important?

The determination of a person's capacity, particularly as a person ages, will have a major impact on that person's life. For applications made to the Family Court, decisions are often made for a person without their direct input or attendance.[283] For an EPOA a decision is made to appoint a person to act as a substituted decision-maker at a time when a person loses capacity, but there are almost no checks and balances operating once that capacity is deemed to be lacking. At common law the capacity assessment test is similar to the functional MCA capacity test. In New Zealand it is the common law test for capacity that applies for an advance directive, arguably just adding another capacity test to the PPPR Act list of tests. (PPPR Act, (s 99A)

---

[277] Queensland guidelines, above n 277, at 16.
[278] At 15.
[279] PAA, s 41(2)(a)-(f).
[280] PAA, s 41 (1)(a) and (b).
[281] PAA, s 42(4).
[282] Collier, Coyne and Sullivan, above n 278, at 17.
[283] PPPR Act, ss 12 and 31.

Other international jurisdictions have a comprehensive statutory framework that includes legislation, regulations, guidelines and processes around capacity and competence that provides the protection for people lacking capacity. The writer argues that New Zealand legislation does not have the necessary protections for people who lack capacity. The lack of a fit-for-purpose statutory framework, the lack of a clear singular capacity definition and a lack of comprehensive guidelines for use in both the legal and medical arenas leaves many people who lack capacity unprotected, and in particular their placements into residential care where often there is no legal authority in place for that person. There is currently no legal process governing loss of liberty for some people lacking capacity.

Loss of capacity and deprivation of liberty

MCA 2005

The human rights issue of deprivation of liberty came to the fore in the Bournewood case involving a 48-year-old man (HL) with severe learning disabilities and autistic traits who was sent from his day care centre to the Accident and Emergency Department of a hospital then was transferred to a psychiatric unit where he was admitted informally because he had not resisted the transfer. The psychiatric unit made a decision that, if HL tried to leave the facility, he would be prevented from doing so.[284] In an earlier case *re F (Mental Patient: Sterilisation*) Lord Goff had extended the use of the traditional common law test of the doctrine of necessity to include medical treatment without consent where certain requirements were met.[285] Initially in Bournewood, the House of Lords found the use of the doctrine of necessity was justified for HL's admission into hospital and any deprivation of liberty that had occurred in the process.[286]

This House of Lords decision was appealed to the European Court of Human Rights [ECHR]. The ECHR applied the United Kingdom's Human Rights Act 1998 (UK) principle that the right to liberty and security was a human right. The ECHR found that when HL was informally admitted to hospital there had been a violation of Articles 5(1) and 5(4) and that there were insufficient procedural safeguards to protect him against an

---

[284] *R v Bournewood Community and Mental Health NHS Trust, Ex p. L* [1998] All ER 289 at 290.

[285] *Re F (Mental Patient: Sterilisation*) [1990] 2 AC 1.

[286] Kim Chandler, Ben White and Lindy Willmott "Safeguarding Rights to Liberty and Security where People with Disability are Subject to Detention and Restraint: A Practical Approach to the Adjudication, Interpretation and Making of Law (Part Two)" (2018) 25(4) Psychiatry, Psychology and Law 550 at 554.

arbitrary deprivation of liberty.[287] The ECHR observed the House of Lords had constrained their conclusions to the legal test of restraint based on false imprisonment, rather than the Convention's conception of deprivation of liberty as in Article 5(1).[288]

This legal loophole became known as the 'Bournewood Gap' and referred to people who lack capacity being deprived of their liberty without their consent, where there is no clear process of legal safeguards in place to protect them.[289] The decision of the ECHR subsequently led to major legislative reform.

Following the ECHR decision, the United Kingdom government decided to close the Bournewood Gap by amending the MCA to include deprivation of liberty safeguards by setting out restrictions around use and when it is necessary to deprive a person of their liberty for life sustaining treatment or a vital act.[290] The deprivation of liberty safeguards [DOLS] are a series of assessments that are undertaken when a person lacking capacity is admitted to a hospital or a care home to provide legal safeguards for them. There is a Schedule A1 for hospitals and care home residents in the MCA and a specific code of practice for the deprivation of liberty.[291]

MCANI 2016

The MCANI also provides a comprehensive statutory framework for people who lack capacity to make a decision for themselves and for those who now have capacity but wish to make preparations for a time in the future when they lack capacity. The issue of deprivation of liberty was further supported by a 2019 code of practice.[292] Anyone who acts in a professional capacity for remuneration, as an attorney under an enduring power of attorney, or as a trust panel member, must also have regard to the code of practice.

---

[287] R Mackenzie and J Watts "Mind the gap: the Deprivation of Liberty Safeguards in the amended Mental Capacity Act 2005" (2010) 15(1) Tizard Learning Disability Review 5 51, at 52.
ECHR art 5(1) states that everyone has a right to liberty. ECHR art 5(4) allows for individuals to seek a review by a court of his or her detention.

[288] Chandler, White and Wilmott, above n 288, at 554.

[289] Mackenzie and Watts, above n 289, at 52.

[290] MCA ss 4A, 4B and 4C.

[291] Mackenzie, and Watts, above, n 291, at 52.

[292] MCANI Code of Practice Deprivation of Liberty Safeguards, November 2019, s 289.

Queensland

In Australia there is varying legislation and practice across the States and Territories and in the past only a few jurisdictions have had Human Rights Acts or Charters,[293] although the landscape in Australia has been changing as it has endorsed the CRPD and other international conventions.

In 2014 a national framework for reducing and eliminating the use of restrictive practices in the disability sector was endorsed by the Commonwealth, State and Territory ministers.[294] The National Framework operates to give jurisdictions individual arrangements that address the use of restrictive practices in disability services.[295]

Queensland is one of four Australian jurisdictions that has had a legislative framework in place requiring lawful authorisation for restrictive practices (the other jurisdictions are Victoria, Tasmania and the Northern Territory).[296] Queensland is the only jurisdiction that requires both evidence of harm to the adult or others in the past, as well as a reasonable likelihood that harm will occur in the future. Queensland imposes time limits where a restrictive plan is implemented to show that the behaviour that is causing harm can be reduced or eliminated, and that the person's quality of life will be improved in the long term. An approval for containment and seclusion by the Queensland Civil and Administrative Tribunal is limited to a maximum of 12 months; an appointment of a guardian for restrictive practices is limited to two years.[297]

In New Zealand

The Bournewood Gap and the issue of the deprivation of liberty for people who lack capacity, remains a significant human rights issue for New Zealand.[298] Section 22 of the NZBORA protects the right of people not to be arbitrarily detained. New Zealand is also a party to CRPD which imposes obligations to support people with intellectual and cognitive impairments to realise their rights to liberty and security.[299]

---

[293] Chandler, White and Wilmott, above n 290, at 555. These were the Victoria Charter of Human Rights and Responsibilities Act 2006 (Vic) and the Australian Capital Territory (Human Rights Act 2004 (ACT).

[294] Australian Government "National Framework for Reducing and Eliminating the Use of Restrictive Practice in the Disability Service Sector" (Department of Social Services, Canberra, 2014).

[295] At 1.

[296] Chandler, White and Wilmott, above n 295, at 565. These practices can include detention, seclusion, physical and chemical restraint of people with disabilities.

[297] At 567.

[298] Fisher, above n 211, at 194.

[299] Chandler, White and Wilmott, above n 299, at 563.

In 2014, the United Kingdom Supreme Court considered whether living conditions and support arrangements of people with intellectual disabilities could amount to a deprivation of liberty for the purposes of the Human Rights Act 1998 (UK). The majority of the Supreme Court found there had been a deprivation of liberty. Lady Hale (now Dame Hale) found that while any deprivation of liberty may have been in the person's own best interests, their living conditions amounted to a deprivation of liberty.

Lady Hale further noted:

> *"…(W)hat it means to be deprived of liberty must be the same for everyone, whether or not they have physical or mental disabilities. If it would be a deprivation of my liberty to be obliged to live in a particular place, subject to constant monitoring and control, only allowed out with close supervision, and unable to move away without permission even if such opportunity became available, then it must also be a deprivation of liberty to a disabled person. The fact that my living arrangements are comfortable, and indeed make my life as enjoyable as possible, should make no difference. A gilded cage is still a cage."*[300]

Lady Hale explained in extra-judicial writings as follows:

> *"The acid test as whether they were under the complete control and supervision of the staff and not free to leave. Their situation had to be compared, not with the situation of someone with disabilities, but with the situation of an ordinary, normal person of their age. This is because the right to liberty is the same for everyone. The whole point about human rights is their universal quality, based as they are upon the ringing declaration in article 1 of the Universal Declaration of Human Rights, that "All human beings are born free and equal in dignity and rights."*[301]

In practice in New Zealand, without a legal framework to provide the necessary legislation and guidelines, the HDC Code Right 7(4) is being used to cover the scenario where a decision needs to be made for a person lacking capacity, and who does not have a named attorney. Right 7(4) of the Code permits treatment based on a best interest assessment to be provided to a person, as long as the views of suitable people who are

---

[300] *P v Cheshire West and Chester Council and P v Surrey County Council* [2014] UKSC 19 at [46].

[301] Lady Hale, "Psychiatry and the Law: An Enduring Interest for Lord Rodger" (The Lord Rodger Memorial Lecture, 31 October 2014) 24. <supremecourt.uk/docs/speech-141031>

interested in the welfare of that person are taken into account. There is no requirement that the treatment is consistent with the views of these people, as long as these views are taken into account.[302]

Although the common law doctrine of necessity can also be argued as providing justification for providing services without consent, the continued use of the doctrine of necessity, and Right 7(4), may not provide sufficient justification in light of Lady Hale's clear edict and New Zealand's obligations under CRPD. There is a view that the extension of the doctrine of necessity is discriminatory to people with intellectual disability and cognitive impairments, who do not have capacity to consent to detention or treatment, in that they cannot rely on the same principles and rights that other people have.[303]

The issue in New Zealand has been highlighted in the residential care sector. There has been no published data on the number of people who reside permanently in residential care without proper legal authority simply because they are unable to consent and have no-one appointed to act on their behalf. In an audit of rest home, private hospital, dementia care and psycho-geriatric private hospitals undertaken by Dr Mark Fisher at aged residential care [ARC] facilities, three hypotheses were tested. First, that a significant proportion of ARC residents would lack the capacity to consent to living in a facility, secondly many incapacitated resident placements would lack any formal legal authority, and thirdly the rates of legal authorisations would be higher in the secure facilities when compared to other open facilities.[304]

The research conclusions confirmed the first two hypotheses, with 65% of ARC residents found to lack capacity to consent to living in an ARC facility with many diagnosed with dementia, stroke or cognitive impairment; and 37.1% of placements not having evidence of proper legal authority.[305] There are many obstacles to making sure that people receiving care have appropriate legal authorities in place, highlighting numerous deficiencies in the current legislation.[306] The PPPR Act has no ongoing process for

---

[302] Mark Fisher and Janet Anderson-Bidois, (eds) *This is not my Home A collection of perspectives on the provision of aged residential care without consent NZ Human Rights* (New Zealand Human Right Commission, June 2018) at 31.
[303] Chandler, White and Wilmott, above n 301, at 554.
[304] Fisher and Anderson-Bidois above n 304, at 14.
[305] At 18.
[306] At 20.

reviewing the detention of people who lack capacity where their detention has been authorised by a person holding an EPOA or a welfare guardian appointed by the Family Court.[307]

In practice it is not unusual a lawyer for subject person, when appointed, to be advised the person is in hospital only to find when first meeting with them the person has already been moved from hospital into residential care after an assessment that they could no longer return to their home, HDC Code Right 7(4) having been used for this placement. The lawyer for subject person's brief ends on the making of a welfare guardian order by the Family Court. With no adequate legislation and regulatory framework in place, there are insufficient safeguards for people who lack capacity.

There are about 34,000 ARC beds in New Zealand and around 5% of over 65-year-olds in care at any one time. This rises to 14% for the 80+ and 50% for the 95+ age groups. Nearly half of the elderly population will go into residential care; New Zealand ARC use is relatively high.[308] The issue around deprivation of liberty is a real and urgent problem exacerbated by a lack of statutory framework and guidelines.

A Medico-legal decision?

Capacity is a legal decision informed by medical and other evidence.[309] While this statement may be correct in theory, in practice it has been suggested that capacity has largely become the domain of the legal expert with this approach been questioned by some.

Case argues that mental capacity is a social construct which does not belong exclusively to any particular discipline, and raises the question as to whether the Courts are simply too ready to defer to medical experts and the evidence they give.[310] With medical experts there can be a tendency to portray a medical opinion as an objective fact; this leaves little room to challenge the expert's view.[311] Case asks whether medical practitioners can tend to be over-inclusive, focusing on consequences and a good clinical outcome, whereas a

---

[307] At 67.
[308] At 1.
[309] *McFadzean v Moleta* [2013] NZHC 1601 per Collins J at [7].
[310] Paula Case "Negotiating the Domain of Mental Capacity: Clinical judgement or judicial diagnosis?" (2016) 16(3-4) Medical Law International 174 at 193.
[311] At 177.

legal perspective may tend to be more concerned with principles.[312] In practice, with applications to the Family Court, there is a clear reliance on the medical report filed, which is not in affidavit form with little other evidence put forward for consideration.

Case supports the need for a multidisciplinary approach in the determination of capacity which involves a robust jurisdiction of the court that is balanced around the evidence presented; relying too heavily on medical judgments can gloss over other relevant factors,[313] especially where there is partial capacity.

To achieve a multi-disciplinary approach in the development of ADs, it is important that legal and health professionals avoid only discipline specific education. There would be substantial potential benefits from a consistent cross-disciplinary approach to professional development.[314] The medical view appears often to have concern around AD documentation and approaches they see as being too legalistic. A combined approach to end-of-life requires some flexibility, but it also needs both legal and medical to have input in the structure and outcomes that provide protections for all.

Because of the burgeoning growth in the aged sector, this combined approach would benefit the people affected, improving AP, AD and EPOA documentation, increasing public knowledge, and would be a way forward to an informed future.

---

[312] At 198.
[313] At 204.
[314] Collier, Coyne and Sullivan, above n 284, at 166.

Ethics

Ethics is about the way a person or social group ought to behave and includes principles and moral standards.[315]

Where this statement is extended to apply to an AD, in particular to its form and interpretation, legal/medical tensions emerge. An AD is legal in its construct, but is usually medical in its application.[316] Legal and medical ethics are quite different disciplines and have developed gradually over many years.

What are legal ethics?

Legal ethics developed as an academic discipline in the mid-1970s, based in moral philosophy.[317] "Moral philosophy is a philosophical inquiry about norms and values, about ideas of right and wrong, good and bad, what should and should not be done".[318]

For lawyers, the discipline of ethics is about decision-making assessed against rightness and the standards, which are then applied to determine the assessment as being right or wrong. There are three ethical subsets that can be applied to an assessment around decision-making: normative ethics (a concern about how we ought to behave), applied ethics (relevant to society's issues and include abortion, euthanasia), and meta-ethics (concerned with the meaning of the moral terms used).[319] For an AD it is the applied ethics that form part of the assessment required.

There are four moral philosophy theories referred to by Scragg for this purpose being Utilitarianism, Kantianism, Intuitionism and Virtue Ethics.[320] It is the philosophy of Immanuel Kant (1724-1804) which gives emphasis and importance to the principle of individual autonomy.[321] From a legal perspective, respect for individual autonomy underpins human rights and principles of freedom, liberty and security.[322]

---

[315] Lesley Brown (ed) The New Shorter Oxford English Dictionary (Clarendon Press, Oxford, 1993) 2 at 3542.

[316] Wilmott, White and Mathews, above n 113, at 367.

[317] Katherine R Kruse, "The Jurisprudential Turn in Legal Ethics" (2011) 108 Scholarly Works 493 at 493.

[318] DD Raphael *Moral Philosophy* (2nd ed, Oxford University Press, Oxford, 1994) at 8.

[319] Richard Scragg, *The Ethical Lawyer legal ethics and professional responsibility* (Thomson Reuters, Wellington, 2018) at 79.

[320] At 79.

[321] At 86.

[322] *Seales v Attorney-General* [2015] NZHC 1239 at 557 [26].

Although Kant wrote in the eighteenth-century Enlightenment period, the principle of autonomy is still applicable today[323] and has become the main legal ethical issue for an AD. Legal academic Mary Donnelly argues that it was both Kant and John Stuart Mill that have impacted the concept of autonomy. Kant, as mentioned above, and John Stuart Mill through his utilitarian liberal vision, are seen in healthcare ethics and law today, even though Mill rarely used the word autonomy.[324]

What are medical ethics?

Medical ethics have their foundation in a different discipline. The Hippocratic Oath, traditionally attributed to the Greek physician Hippocrates (460-370BC), is seen as an early expression of medical ethics in the Western world.

Medical ethics today are largely expressed by four principles developed by Beauchamp and Childress: autonomy, non-maleficence, beneficence, and justice.[325] Autonomy recognises the rights of a patient to make decisions for themselves; beneficence requires a doctor to achieve the best outcome for a patient, while recognising resource constraints; non-maleficence implies a duty to do no harm; justice incorporates notions of equity and the fair distribution of resources.[326]

New Zealand also recognises the principle of partnerships between doctor and patient, profession and society, different cultures and te Tiriti o Waitangi.[327] While each of the principles is regarded as being individually important there will be situations where one principle may override the others. Autonomy is now generally regarded as the dominant principle in medical ethics[328] with consensus that the patient's choice to refuse treatment (autonomy) would prevail over a doctor's recommendation that medical treatment is required to improve a patient's health (beneficence).[329]

---

[323] Allen W. Wood "What is Kantian Ethics?" in Allen W Wood (ed and translated) and others *Groundwork for the Metaphysics of Morals Immanuel Kant* (Yale University Press, 2002) at 157.

[324] M Donnelly *Healthcare Decision-making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, Cambridge, 2010) at 19.

[325] L Beauchamp and JF Childress *Principles of Biomedical Ethics* (7th ed, Oxford University Press, New York, 2013).

[326] NZMA Code of Ethics for the New Zealand Medical Profession (2020) at 2.

[327] At 2.

[328] Wilmott, White and Mathews, above n 318, at 379.

[329] At 380.

The importance of autonomy today contrasts with the 1950s paternalistic medical practice where a doctor would mainly make the treatment decision for a person. The change from this model to a focus on patient autonomy has created a number of ethical issues for a doctor treating the older person with high dependency, or in the management of life-threatening situations.[330] The concept of individual autonomy as being '… self-rule that is free from both controlling interference by others and limitations that prevent [the individual from making] meaningful choice[s] [about his or her body]' was argued in *Seales v Attorney-General*.[331]

Where a person has capacity, and has given instructions that there is no consent to treatment, the patient's wishes must be followed.[332] The patient's choice to refuse treatment prevails over beneficence, and the doctor's recommendation that medical treatment is required to improve the patient's health.[333]

Ethics around future decisions - the Margo factor

There has been much debate and argument around a person's status where they have lost capacity, and whether the person who no longer has capacity is the same person as their past self.

This question arose in the case of 64-year-old Margo. Margo had signed an AD many years before when she was competent, which included a direction that if she developed Alzheimer's disease she should not receive treatment for any other serious or life-threatening disease she might contract, and if she did, that she should be killed as soon and as painlessly as possible.[334] Margo did develop Alzheimer's disease, but appeared to enjoy food and a set of daily repetitive activities. The ethical issue arose when Margo became ill with pneumonia where if she did not receive treatment she would die.[335]

---

[330] Arnold J Rosin and Moshe Sonnenblick "Autonomy and paternalism in geriatric medicine. The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation" (1998) 24 Journal of Medical Ethics 44 at 44.

[331] *Seales v Attorney-General* [2015] NZHC 576 at [71].

[332] *Re AK (Medical Treatment: Consent*) [2001] FLR at 134.

[333] Wilmott, White and Mathews, above n 331, at 380.

[334] Margo's case was described by a medical student in Firlik AD, "Margo's Logo" (19901) 265 JAMA 201.

[335] R Dworkin *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins, London, 1993) at 218-241.

Is the Margo with Alzheimer's, who appears to be happy with some enjoyment in repeated daily activities, a different person from the person who made the AD?

For Professor of Jurisprudence, Ronald Dworkin, the answer was quite clear; Margo's AD should be followed and her pneumonia not be treated with antibiotics. Dworkin's view is that each person is responsible for their own life and the person retains that earlier freedom at the later time in the future.[336]

Dworkin makes a distinction between a person's critical interest (a value judgement about their life as a whole) and their experiential interest (the quality of a person's experience from moment to moment).[337] For Dworkin, Margo's decision to make an AD while she was competent is a precedent autonomy.[338]

Dworkin describes Margo's earlier self-expression as an integrity view of autonomy, which he perceives to be more powerful than an evidentiary view of autonomy. It is the integrity view of autonomy that allows people to live their lives in a way they choose, even if that conflicts with their best interests.[339] Dworkin believes the person making the AD has spent time considering what their wishes and preferences are; a decision made when competent to refuse treatment should be respected.[340]

Dutch philosopher Govert den Hartogh agrees with the authority of an AD and generally agrees with Dworkin's view of critical and experiential interests of a person and that the critical interests take precedence. Den Hartogh, however, sees situations arising where a critical interest may not take precedent over the experiential interest. For example, where an AD instructs that no palliative care should be provided to a severely suffering Alzheimer patient. For den Hartogh the personal value or disvalue of an Alzheimer's patient has to be decided in terms of his categorical interests, and these can only be determined from the views about his life as a whole which he had when he was still

---

[336] Ron Paterson "Advance Decisions" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) 352 at 378.
[337] Govert den Hartogh "The Authority of Advance Directives" in Denier Y, Gastmans C and Vandervelde A. (eds) *Justice, Luck & Responsibility in Health Care* (Library of Ethics and Applied Philosophy, London, 2013) 167 at 169.
[338] Paterson, above n 338, at 377.
[339] Wilmott, White and Mathews, above n 335, at 384.
[340] At 383.

capable.[341] Den Hartogh has carried a living will around with him since the 1980s. When den Hartogh considered his reasons for this he looked at the possibility of a permanent loss of ability to perform mental activity and to communicate or live an independent life. His views were formed looking towards an advanced stage of Alzheimer’s or another form of dementia. Den Hartogh recalled his mother-in-law with dementia and possibilities of permanent confusion, disorientation, an inability to put on shoes, fear, paranoia, restlessness, hours spent looking for things. However, all these things by themselves were not the reason for his carrying a living will with him at all times. Den Hartogh carried around his living will at all times as he did not want the final stage of his life to be a part of his biography that he would be remembered for.[342]

Professor of Ethics Rebecca Dresser argues that the decisions that affect a demented person at a given time should be the ones that represent the person’s views at that time. Dresser believes it would be unfair to Margo to hold her to her earlier wishes, when she no longer cares about the things she did before her dementia progressed.[343] As Margo remains able to enjoy and participate in life in some way, directives to hasten death should sometimes be disregarded. Dresser worries about a possible impact on society if the concept of critical interests and precedent autonomy became public policy. Her main concern is for people who change their view when they find out they have a medical condition. There needs to be a recognition that people have very different views on life, and how they plan and structure their lives.[344] With Dresser’s view that a patient’s earlier preferences should not be taken into account it is unclear how that position would be addressed, for example where a person with strong religious beliefs had decided not to make an AD but who, when suffering from dementia, expresses a wish that he wants his life to end.[345]

Legal academic Mary Donnelly notes that a person with dementia can become quite a different person, and that can influence our view of their previously stated wishes.[346] Donnelly suggests some caution around allowing people with impaired capacity to

---

[341] Den Hartogh, above n 339, at 173.

[342] At 168.

[343] Agnieszka Jaworska “Respecting the Margins of Agency: Alzheimer’s Patients and the Capacity to Value” (1999) 28(2) Philosophy & Public Affairs 105 at 108.

[344] Rebecca Dresser “Dworkin on Dementia: Elegant Theory, Questionable Policy” (1995) 25(6) Hastings Cent R 32 at 32.

[345] Jaworska, above n 345, at 107.

[346] Donnelly, above n 326, at 195.

change their minds. She advocates a narrower rights-based view of autonomy that is not simply a test of whether a person has capacity or not. In Donnelly's view autonomy would be less legalistic and more nuanced to the person.[347]

For Agnieszka Jaworksa, psychiatrist and philosopher, it is about the importance of acknowledging that a person's value is not completely lost in dementia, and that a person may still be capable of a degree of autonomy around their own well-being. Jaworksa associate's autonomy with the person's capacity to value, and wellbeing as living in accordance with their own values. This is compared to Dworkin where autonomy is derived from a person's decision-making capacity, and well-being is viewed over their life as a whole and their own design for their life. In Margo's situation respect should be shown for her immediate interests and this is not contrary to either her wellbeing or her autonomy.[348] For Jarworska, as long as a person can still value part of life, any decisions being made should consider this. The AD decision for dementia is not the same as one made in anticipation of loss of consciousness. An AD for loss of consciousness is clear as to the circumstances, and there are no other interests that have to be taken into account. For the person with dementia an AD is made anticipating values will change for the worse in the future. For Jarworska, upholding an AD represents a person trying to hold his or her future self to current values where others are having to promise that they will up hold those values and enforce them even though at that time they may be against the persons will.[349]

The writer supports Dworkin's view that Margo's AD should be followed, with her critical interest, expressed when competent, taking precedence over her later experiential interest. Dworkin in his writings over time always placed human dignity at the centre of the moral inquiry.[350] Margo's AD was made in anticipation of her becoming demented in the future, with her having some control over what would happen to her as a demented person and to guard against people deciding to follow any of her later expressed wishes she made as a demented person. To not follow Margo's AD and provide treatment for her pneumonia is arguably to disrespect her life lived, her experiences, and her values that led her to making an AD. Jaworska's views are acknowledged and the question she asks

---

[347] Paterson, above n 340, at 379.
[348] Jaworska, above n 347, at 109.
[349] At 137.
[350] Ronald Dworkin obituary The Guardian 14 February 2013.

is ‘at what point in the course of dementia are the attributes essential to agency lost?’[351] The question poses ever-present considerations and an ever-present dilemma.

As people age there is an increasing risk of a progressive and/or degenerative disease dominating the last years of life. A fear of loss of personal autonomy and a perceived loss of our human dignity can prevail. It is the AD that can provide the structure to make future medical decisions, which reflect a person’s beliefs and views from their experience of life. Balancing the different legal and medical ethical theories should not operate to dilute the principle of autonomy and prevent a person from determining the course of their own end-of-life care.

In assessing where theory connects with practical consideration views can become polarised. For example, Parfitt’s reductionist view of identity where he argues there is no continuity or connectedness between the competent person and the person then without competence. If continuity or connectedness do not exist at the same time then the person may be regarded as a completed different entity. Where this view is applied to an AD there is insufficient connection between the competent person and the incompetent person to regard previous directions as being binding.[352] Donnelly and Jaworska are in agreement that where the test for capacity simply divides people into two groups, being those with capacity or those without capacity, that assessment and division is too narrow.[353]

In a recent 2020 case by the Supreme Court of The Netherlands[354] the issues raised are relevant to the Margo discussion. A 74-year-old woman was suffering from deep dementia and was not mentally competent. She had filed a written euthanasia declaration upon learning that she had the onset of dementia. Her declaration said that she did not want to be placed in an institution for the demented elderly, that she wanted a humane farewell for her loved ones, and she later added to her declaration that she wanted euthanasia to take place when she herself considered the time was right.[355] When the time came the doctor had added a tranquiliser to the woman’s coffee and had family members hold her down for the fatal injection; the doctor said she was following the woman’s

---

[351] Jarworska, above n 351, at 137.
[352] Derek Parfitt *Reasons and Persons* (Clarendon Press, Oxford, 1984) at 204-209.
[353] Dresser, above n 246, at 32.
[354] Case C-19/04910 Supreme Court Judgment: *ECLI:NL:PHR:2020:712.*
[355] Toronto Star 29 Aug 2019 RAF Casert and Aleksandar Furtula The Associated Press.

directive. The issue that arose was whether the woman’s resistant behaviour was an indication that she no longer consented to euthanasia.

The case was initially referred to The Hague, Netherlands, Public Prosecutor‘s Office to prosecute the doctor for breaching the euthanasia law including making insufficient efforts to find out whether the woman still wanted to die. There was no subsequent prosecution or finding that there had been a breach of the law and the charges against the doctor were withdrawn. It was decided the Attorney General would proceed with the claim filed in the Disciplinary Court (19/05016) to give the Supreme Court the opportunity to give guidance and to develop the law regarding euthanasia, and in particular with regard to patients with advanced dementia.[356]

The ethical arguments in this case are similar to those argued for Margo. Both women had advanced dementia, both women had given advance directions while competent, and arguably both had had the intention that their directive would be honoured and their autonomy respected and their wishes followed.

How the Courts view autonomy and other ethical questions

The English Courts have recognised the difficult balance to be struck between the principle of respect for autonomy and the preservation of life, noting in *HE v A Hospital NHS Trust* that:

> *Too ready a submission to speculative or fanciful doubts will rob advance directives of their utility and may condemn those who do not want to be treated to indignity or worse. Too skeptical a reaction to well-founded suggestions that circumstances have changed may turn an advance directive into a death warrant for a patient who in truth wants to be treated* [357]

Seales v Attorney General

While this case is about assisted dying when one has capacity to make a choice, the principles argued are relevant to the discussion of ADs.

---

[356] NZLS library did not have a full translation for the case. Advice given by email on 3 August was the Court would consider translating the case after the summer recess.

[357] *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), 2 FLR 408 at [46].

Ms Seales was aged 42 and dying of an inoperable brain tumour. She was partially paralysed, visually impaired and dependent on others for many day-to-day needs; she maintained she was not depressed, nor was she vulnerable. Ms Seales wanted to have the option of being able to determine when she died and sought declarations on the meaning of two provisions in the Crimes Act 1961 in relation to any offence that might be committed by her doctor should he assist her to die. The propositions put were: first, if Ms Seales administered to herself a fatal drug and secondly; if her doctor facilitated aid-in-dying by providing her with a fatal drug.[358] While both declarations were declined, this 2015 case subsequently supported a successful 2020 referendum held in New Zealand. From 7 November 2021, the End-of-Life Choice Act 2019 allows people with a terminal illness, who meet eligibility criteria, to request medication to relieve their suffering and end their life. The Act sets out a legal framework, process and safeguards for accessing assisted dying.[359]

It is submitted that the four fundamental principles argued in *Seales v AG* (the sanctity of life, respect for human dignity, respect for individual autonomy and the protection of the vulnerable) can be overlaid onto the discussion around ADs. Two of the principles, the sanctity of life and respect for individual autonomy, are ethical principles that arise when people no longer have capacity.

Sanctity of life

While sanctity of life was said by Blackstone in 1765 to be the first rule of English law[360] it is not an absolute principle. In *Airedale NHS v Bland,* Tony Bland had been injured in the Hillsborough football stadium disaster. He had lost all sense of self, was permanently unconscious, was being kept alive by a gastric feeding tube and was unable to speak for himself. The Court considered they should try to do what they thought Tony Bland would have chosen

In recognising the limits of the sanctity of life Lord Keith said:

> *"The principle [of the sanctity of life] is not an absolute one. It does not compel a medical practitioner on pain of criminal sanctions to treat a patient, who will die if*

---

[358] *Seales v Attorney-General* [2015] NZHC at 557.

[359] Ministry of Health "Assisted Dying Service". <health.govt.nz/our-work/life-stages/assisted-dying-services>

[360] Blackstone's Commentaries on the Laws of England (Clarendon Press, Oxford, 1765) vol 1 at 130.

> *he does not, contrary to the express wishes of the patient … It does not compel the temporary keeping alive of patients who are terminally ill where to do so would merely prolong their suffering…"*[361]

In cases where an AD is valid and applicable, the patient's wishes should override the principle of the sanctity of life.[362] Decisions will always need to be made to provide a counter balance to the principle of the sanctity of life, as even traditionally conservative thought does not hold fast to a view of saving lives in all circumstances.[363] It is lawful for doctors to withdraw futile medical services to patients in circumstances where it is known the patient will die without those services.[364] In these circumstances treatment must offer a substantial benefit to the person, as determined by that person. The benefit must also be both substantial enough and current enough and then assessed against a likelihood of an unacceptable risk of a bad outcome.[365] This matter has been considered by the New Zealand courts where it was accepted that Other New Zealand cases that have considered these issues are *Auckland Area Health Board v Attorney-General*[366] and *Shortland v Northland Area Health Board Ltd*[367] where the Courts have accepted standard medical practice over the sanctity of life.

Respect for individual autonomy

The Seales case also relied on the principle of respect for autonomy. The NZBORA, s 11 provides for a right to refuse medical treatment. In the decision of the Supreme Court of Canada, *Carter v Canada (Attorney-General)* linked individual autonomy with dignity so where the rights to liberty and security of the person is a concern for the protection of individual autonomy and dignity.[368]

Case studies

How do ethical, legal and medical principles apply in everyday practice? The following three composite case studies are made from observations in practice.

---

[361] *Airedale NHS Trust v Bland* [1993] AC 7890 (HL) at 859.

[362] HE v A Hospital Trust [2003] EWHC 1017 (Fam), [2003] 2 FLR 408 at [32].

[363] Grant Gillett Sanctity of Life, A Sense of Life and Good Endings (2006) 6(2) Law and Justice Journal 243 at 245.

[364] Seales, above n 360, at 564 [16](1).

[365] Gillett, above n 365, at 246.

[366] *Auckland Area Health Board v Attorney-General* [1993] 1 NZLR 235 (HC) at [36].

[367] *Shortland v Northland Area Health Board Ltd* [1998] 1 NZLR 433 at [35].

[368] *Carter v Canada (Attorney-General), 2015* SCC 5, [2015] 1 SCR 331 at [64].

Case Study 1: Mrs D

Mrs D was diagnosed with dementia in her late seventies and remained living at home with progressive dementia. At 88 years of age Mrs D suffered a major stroke and was transferred to hospital care at a residential care facility, where she died two years later, aged 90. During the two-year period of residential hospital care Mrs D was unable to verbally communicate, was bed ridden, unable to feed herself and was fed by staff. Mrs D developed bed sores which would not heal, did not recognise any of her family and had no recollection of her previous life. Mrs D's previous occupation had been in nursing, she had made comments to family members on many occasions that she did not want her life to continue if she was unable to make decisions for herself. Mrs D had an EPOA in relation to personal care and welfare. She received standard medical care at the residential care facility, which included, influenza injections and other life sustaining medications.

The issue is whether Mrs D would have chosen this for her end-of-life care. Without an AD her earlier views became irrelevant, and her ability to make choices when she no longer had capacity were made by others.

Case study 2: Mrs M

Mrs M was diagnosed with vascular dementia at age 89, following a mild stroke and was moved from her own home into a residential care facility. After two years, at 91, she was transferred within the residential care facility to the dementia unit. At 93 years Mrs M suffered a major stroke and was transferred from the residential care facility on a Sunday night to the local city hospital, as there was no doctor on site at the facility. At the hospital staff indicated that Mrs M's stroke was not survivable and that she was likely to die within the next 48 hours recommending she remain in the hospital as she was too unstable to return to the care facility. Mrs M died seven days later, still in the hospital.

Mrs M had an AD which family made available and which was discussed with hospital staff. The AD included Mrs M did not want any interventions other than medication to keep her comfortable should she suffer a non-survivable stroke. During the week Mrs M appeared to be in some distress; she struggled for breath and was moaning as if in pain. The family were upset by Mrs M's apparent distress and requested a reassessment of her situation; she was then given additional comfort medication.

The issue for Mrs M was whether her AD did impact the circumstances of her end-of-life care and her subsequent death in hospital. While the AD assisted in conversations between medical staff and family around her treatment, the transfer to hospital following a major stroke caused unnecessary pain and distress for Mrs M, and meant that her end-of-life was not in accordance with her stated wishes not to die in hospital.

Case study 3: Mr B

Mr B, aged 86 years, was living independently at home when he suffered a severe stroke and was admitted to hospital. The geriatrician at the hospital determined Mr B was unable to return home due to significant cognitive impairment sustained, and he was transferred to a local care facility.

Mr B had four adult children, two of whom were close to Mr B and had regular contact over the years. One child was estranged from the family and the other child, regarded as being difficult [Child 4], moved back home after Mr B's stroke after living out of the city area. Child 4 believed that Mr B would recover from his stroke and be able to return to his home; the medical report said otherwise. There were no EPOAs in place, nor was there an AD. Child 4 applied to the Family Court to be appointed as Mr B's welfare guardian; two of the siblings opposed the application. Due to the family conflict the care facility had to manage different visiting times for family members and care decisions became difficult. Eight weeks later Mr B suffered another major stroke and, due to the unmanageable level of family conflict, Mr B was transferred to the city hospital where he died eight days later, still in the middle of family conflict.

The issue for Mr B was whether an AD, together with EPOAs, may have made a major difference to his end-of-life care which would have been more in line with his wishes and his family values; the documents and the discussions may have resulted in a less conflicted family.

A Sense of Life

"The right to life is more than existence, it is a right to be treated as a human being with dignity: without dignity, human life is substantially diminished."[369] It is well established

---

[369] *Stransham-Ford v Minister of Justice* [2015] ZAGPPHC 230 (HCSA) at 16.

that ultimately the right of the individual is paramount. In Re T (Adult: Refusal of Treatment) Lord Donaldson MR commented:

> *The situation gives rise to a conflict between two interests, that of the patient and that of the society in which he lives. The patient's interest consists of his right to self-determination – his right to live his own life how he wishes, even if it will damage his health or lead to his premature death. Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramoun*t.[370]

There are many ideas of a good life, a good death and dying well. While academics observe, research and write papers on these issues, the individual must continue to be asked what it is they want.[371]

Ethical considerations are more complicated for the person who has lost capacity and has not recorded their views in an AD or EPOA. The reasons for not doing so are varied, from lack of information, different cultural backgrounds, and lack of discussions around death. In a world where individual autonomy is respected, the view of continuing independence does not always reflect our inevitable future reality.[372] Decisions that we need to make, as our life progresses, need to represent our sense of a good life and, for our end, our good endings.[373]

Summary

Where it is accepted that autonomy is the main legal ethical issue for an AD[374] and that autonomy is the dominant ethical principle in medical ethics,[375] how then is the principle of autonomy being promoted and experienced in the legal and medical arena? Ethics must apply in practice as well as in theory. The writer's view is that legal ethics, while providing a duty to clients in practice, must also assist in the development of a statutory framework for ADs to be completed while a person is competent, that also protects that

---

[370] Re T (*Adult Refusal of Treatment*) [1992] 4 All ER 649, [1992] 3 WLR 782; [1993] Fam 95 at 112.

[371] HC Hangar and others "Stroke patients' views on stroke outcomes: death versus disability" (2000) 14 Clinical Rehabilitation 417 at 421.

[372] Atul Gawande *Being Mortal Illness, Medicine and What Matters in the End* (Welcome Collection, London, 2014) at 22.

[373] Gillet, above n 367, at 243.

[374] Wilmott, White and Mathews, n 341, at 371.

[375] At 379.

autonomy when the person is no longer competent while giving certainty to that future outcome. In medical ethics, while a doctor must have autonomy and clinical independence to exercise professional judgement, and must follow the duty of care to first do no harm, an AD that is valid and applicable must be followed.

Care of a person lacking capacity will always involve competing ethical views that impact the decisions made. To achieve this balance medicine and law need to work closely together[376] as well as hearing what the patient is saying.

---

[376] Gillett, above n 375, at 247.

Forms

While the PPPR Act gives statutory authority for an AD in New Zealand, there are no prescribed forms, directions or operating guidelines given for their use in either the PPPR Act or under the HDC Code.

This section compares three different formats used for an AD in three different jurisdictions. First, the prescribed AHD used in Queensland, Australia under the Powers of Attorney Act 1998, where the form is part of the legislation. Secondly, New Zealand ACP form My Advance Care Plan & Guide used in the health system, usually where there is a serious health issue. Thirdly, the MCA with legislation in place for an AD where the precedent form, while not prescribed in the legislation, is supported by it, with comprehensive guidelines and checklists.

Queensland forms

Queensland has two relevant pieces of legislation operating for their capacity law, being the PAA and the GAA; the legislation is linked and each makes mention of the other.

The PAA has consolidated, amended and reformed the law about general powers of attorney, EPOAs and providing for AHD and for other purposes.[377]

The GAA seeks to strike a balance between the right of an adult with impaired capacity to the greatest degree of autonomy in decision-making, and the adult's right to adequate and appropriate support for decision-making.[378] The Act is read in conjunction with the PAA which prevails if there is an inconsistency.[379]

Under the PAA anyone over 18 years of age who is capable of understanding the nature of their directions, and foreseeing the effects of those directions, can generally make an AHD.[380] The PAA provides for the making of a power of attorney, an EPOA and an AHD [381] and sets out how an AHD operates.[382] This legislation does not affect the common law position for an AHD.[383]

---

[377] PAA, Headnote.
[378] GAA, s 6.
[379] Section 6A.
[380] PAA, s 44(2). ADH form 4.
[381] Sections 8, 27 and 35.
[382] Section 36.
[383] Section 39.

An EPOA it must be in a prescribed form,[384] with specific signing and witnessing provisions for completion of a valid document.[385] There is provision for an EPOA to be proved by being certified.[386]

An AHD must be in writing and may be in the approved form.[387] A doctor must sign and date a certificate confirming the person appears to have the necessary capacity at this time.[388] The Court's powers are set out in s 110-125. The Court may decide the validity of a power of attorney, an EPOA or an AHD.[389] Capacity is defined in the Schedule 3 Dictionary.

Queensland was aware that just because legislation was in place there was no guarantee an AHD would be used.[390] Queensland's AHD form was drafted after considerable consultation around the design with representatives of all the main stakeholder groups, including older people, health and legal professionals and ethicists. The form takes into account existing legislation in the relevant jurisdictions.[391]

The focus on the form design and layout was to ensure the form itself did not become a barrier to use. It had to be suitable for recording advance wishes, not too simplistic or evaluative in terms that could be interpreted differently when executed, use language not too difficult or too technical for non-medical people to understand, and the form not too rigid or too prescriptive by leaving no room for reasonable interpretation in unforeseen situations. The aim was simplicity, clarity and length of the document, inclusion of appropriate safeguards and suitability for medical and legal requirements. A form may be too general or too vague where it is limited to statements of values, without specific examples for guidance.[392]

---

[384] Section 44(1).

[385] Section 44(3)-(5).

[386] Section 45.

[387] Section 44(2).

[388] Section 44(6).

[389] Section 113.

[390] Collier, Coyne and Sullivan, above n 316, at 83. Although South Australia had had 11 years of legislation for AHD their use was low.

[391] At 84.

[392] Collier, Coyne and Sullivan, above n 392, at 84.

The Queensland form is a 23-page document that has informative and easy to read explanatory notes. The terms used are defined in clear language and a context is provided for decisions to include or refuse treatment. Life sustaining treatment is clearly defined. The form is quite prescriptive and has specific questions for refusal for treatment such as 'If I am in the terminal phase of an incurable illness I do/I do not want cardiopulmonary resuscitation'.[393]

While there are some unresolved issues around AHDs, this has not prevented legal development in the area and it is generally agreed that the crafting and implementation of AHDs requires sensitivity, reflection and flexibility on everyone's part.[394] The AHD also has a section for a personal statement about any particular wishes of preferences. The form is well set out, easy to read, clear in the instructions with and explanatory guide to follow. Other issues such as tissue donations are raised. There is a strong recommendation that the form is discussed with the doctor before it is completed. The doctor must sign and the form must be separately witnessed. Details of any EPOA are recorded on the form.[395]

There is a Guardianship and Administration Tribunal and Office of the Adult Guardian. The powers of the Adult Guardian include extensive powers of investigation, mediation and conciliation, finding assistance and acting as attorney for the person with impaired capacity; these apply to both EPOAs and AHDs.[396]

New Zealand Advance Care Planning form

ACP has a form called My Advance Care Plan & Guide: *Plan the healthcare you want in the future and for the end of your life.* It is a sixteen-page document divided into seven sections: my advance care plan, what matters to me, why I am making an advance care plan, how I make decisions, when I am dying, my treatment and care choices, and after my death.[397]

---

[393] PAA, s 44(2), Form 4 at 10.

[394] Collier, Coyne and Sullivan, above n 394, at 85.

[395] PAA, s161.

[396] Collier, Coyne and Sullivan, above n 396, at 25.

[397] My Advance Care Plan & Guide: Plan the healthcare you want in the future and for the end of your life. <hqsc.govt.nz/assets/ACP/PR/ACP_Plan_print_.pdf>

The form identifies the person and the healthcare team that will work together in caring for the person, and that whānau and loved ones make decisions about care if the person can no longer tell them what they want. The person is encouraged to write what makes their life meaningful, what is important to them, what are the worries about health and dying, what being ill might mean, any additional information including who may need to be advised.

There is a reference to an EPOA, but it makes no mention of which health decisions cannot be made under an EPOA. The form requires a choice between five treatment and care options: CPR, focus on quality of life (no resuscitation), focus on comfort and dignity (no resuscitation), healthcare team to decide treatment in consultation, and, if none of the above, there is a direction to the AD on page 11.

This section asks for treatment preferences in specific circumstances. The example given is: if the person has a severe stroke and is unable to recognise anyone, is the care to focus on a natural death with comfort measures provided, and would it include artificial feeding? There is no list or information provided on other possible medical options to assist a person to make their choice and no glossary of definitions to assist.

The wider vision for ACP is that everyone in New Zealand will understand the need for an advance care plan throughout their lives; it will not be a document used only for a health consumer in the event of a serious or terminal illness.[398]

The factors identified as important for the AC Plans in Australia, that are relevant to New Zealand considerations, include: the AC Plan is a written document which should be given proper consideration by clinicians; there must be evidence that the person was not unduly influenced; where statutory witnessing provisions are followed, the plan has more credibility; a regular review of the AC Plan provides more certainty about its currency, and is more likely to relate to a current condition. An AC Plan that clearly contemplates the current clinical circumstances will reduce doubt about its applicability; and where it

---

[398] Conversation with a senior geriatric consultant in 2021.

is appropriately worded, an AC Plan will be stronger if it avoids vague or imprecise language.[399]

In New Zealand an AC Plan predominantly applies to the health consumer with a serious or terminal illness. The person may well be elderly, fragile, scared, confused and have the additional stresses of a serious health situation when completing the ACP form. In comparison to the Queensland form, the New Zealand form could be argued to be too general and too vague as it asks people to express their preferences and values, and to make care decisions without specific examples for guidance. The form will not be suitable for use by everyone, due to the format and the language used.[400]

One of the issues around the AC Plan form is that, without any specific code of practice, administrative or judicial reviews, or checks and balances, there is a lack of protection in place for the vulnerable person. It appears that many decisions are made on the best interest test with family input. It may be that, with no prescribed form, more decisions are being made as best interest decisions by the clinician and family; this could be seen to be a step back to the more paternalistic model of doctor led health and away from the principle of autonomy. A geriatrician has noted that the current AC Plan form is not prescriptive and allows flexibility, which is preferred. While ADs are being made with the AC Plan form, there is no case law around these decisions and their use.

MCA forms

The MCA includes LPAs for personal welfare and property and affairs,[401] and AD.[402] It is clear in the legislation an AD does not apply to life-sustaining treatment unless the decision is verified by a statement that includes that the person wants the AD to apply to that treatment even if life is at risk; that statement must be in writing, signed and witnessed.[403]

While there is no prescribed form for an AD under the MCA, there is a suggested precedent form which is available to use; it is an enabled online form with automated

---

[399] Rachel Z. Carter and others “Advance care planning in Australia: what does the law say?” (2015) 40 Australian Health Review 405 at 412.

[400] In practice the AC Plan form was found to be quite vague and not easy to complete.

[401] MCA, ss 9(1) & (2).

[402] MCA, s 24.

[403] MCA, ss 25(5) & (6).

clause numbering and cross-referencing for easy use.[404] A solicitor's checklist of points to consider when drafting an AD is also available for easy use.[405] The solicitor's checklist includes the following: introductory matters, record of discussions, dating and edition, capacity issues, circumstances in which the decision should apply, treatment covered by the decision, the reasons for the decision, other wishes and statements, life-sustaining treatment, persons to be consulted, signatures and witnessing, what cannot be included in an AD, review and letting people know about it. The MCA the advance decision to refuse medical treatment under the Mental Capacity Act 2005 (long form) has a form and applies to life-sustaining treatment.

The legislation has comprehensive guidelines that apply to both legal and health areas linking the legal framework to the practical outcomes for all users.[406]

Comment

The three systems work very differently but with the same goal for options for the person at end-of-life. There are forms to be used but not prescribed in each of the jurisdictions. The comparable differences in the forms and their use relates mainly to the fit-for-purpose legislation for capacity and for those who lack capacity and comprehensive guidelines that provide examples of how the legislation applies in certain situations; this applies to the PAA and GAA and MCA.

New Zealand is more exposed without the necessary statutory framework in place and a lack of comprehensive guidelines around capacity and for people who no longer have capacity. It could be argued that the form of the AC Plan is too general and vague, in a format that is not easy to read, has little definition of the terms used, provides few examples around choices to be made and appears to be trying to be everything to all. The language used in the AC Plan form may suit many, and in particular for conversations around illness and terminal illness. The writer argues that an AD needs to operate in both the legal and health arena and not be narrowed to people at a particular time in life, but

---

[404] Advance decision to refuse medical treatment under the Mental Capacity Act 2005 – long form reference EFP 42(3): 12/2016.

[405] Solicitor's checklist of points to be considered when drafting an advance decision to refuse medical treatment under the Mental Capacity Act 2005. Reference EFP 42(3): 12/2016.

[406] Mental Capacity Code of Practice, above n 262, at 1-301.

rather to be more age specific in focus when a person is well; our current practice does not necessarily provide the autonomy guaranteed by the NZBORA and the common law.

Geriatricians spoken to noted that they generally like the AC Plan form because it is not too prescriptive but worry that an AD maybe too prescriptive. One geriatrician of 20 years practice, however, had only ever seen five ADs in that time.

Development of this area must also consider how forms will be stored in electronic medical records where there must be integration into workflow, software usability and relevance of the content to the patient at hand.

Who makes an Advance Directive?

It has been found that once an advance choice is made, that choice remains stable over time and that generally people are willing to accept the future choice they have made and accept the risks around that choice in preference to the risk of receiving unwanted treatment.[407] What is less certain is when might be an optimal time to complete an AD.[408] If completed too early there may be no certainty around care options available in the future. A younger person may underestimate the quality of life they may be willing to accept at a later time.[409] If ADs are only completed when there is already a health issue the doctor may be able to provide realistic guidance; however, if the conversation is only raised when a person is given bad news, this may negatively impact the decisions made.[410]

A 2017 study found that in ADs completed 10 years before death there was a lower rate of preference for aggressive care and a stronger preference for limited care.[411] The ADs completed in the last three months of life were associated with a higher rate of preference for aggressive care often electing to try all possible means to prolong the person's

---

[407] Jeffrey l. Schnipper and others " 'Smart Forms' in an Electronic Medical Record: Documentation-based Clinical Decision Support to Improve Disease Management" (2008) 15(4) Journal of American Medical Informatics Association 513 at 513.

[408] Collier, Coyne and Sullivan, above n 398, at 86.

[409] At 85.

[410] At 86.

[411] Susan Enguidanos and Jennifer Ailshire "Timing of Advance Directive Completion and Relationship to Care Preferences" (2016) 53(1) Journal of Pain and Symptoms Management 49 at 53.

survival.[412] Patients with ADs are more likely to receive care that is consistent with their wishes and that reflects their values and their prognosis.[413]

In a 2000 New Zealand study of 28 elderly stroke patients, their views on death and disability were compared with the views of an age and sex matched control group who had never had a stroke or transient ischemic attack.[414] The study considered whether once a stroke patient is confronted with the reality and immediacy of disability, they would have an increased tolerance of a disability and be less likely to want to die than the control group who had not had a stroke.[415] The majority of elderly patients feared severe disability more than death with the control group expressing a similar view.[416] The conclusion was that many elderly people would rather die than be severely disabled.[417] However, an earlier study had noted that where the outcome of an event was less severe, the person could adjust to their situation, and death was less preferable.[418]

In a 1991 United States study of 405 outpatients and 102 members of the general public, 93% of the outpatients and elderly wanted some form of planning for their health care, including having an AD, as did 89% of members of the general public.[419] Of the 93% of outpatients only 15% had already undertaken any form of planning. The study found that while there were compelling reasons for ADs, very little was known about their actual use.[420]

In a later 2017 study only one in three United States adults were found to have completed any type of AD for end-of-life care.[421] This study reviewed and analysed studies published between 2011-2016 that reported completed AD among US adults.[422] Some

---

[412] At 54.
[413] At 50.
[414] HC Hangar and others "Stroke patients' views on stroke outcomes: death versus disability" (2000) 14 Clinical Rehabilitation 417 at 417.
[415] At 419.
[416] At 421.
[417] At 417.
[418] Dennis J. Mazur "Patients' Willingness to Accept Life-Sustaining Treatment When the Expected Outcome is a Diminished Mental Health State: An Exploratory Study" (1996) 44(5) Journal of the American Geriatrics Society 565 at 565.
[419] Linda L. Emanuel and others "Advance Directives for Medical Care – A Case for Greater Use" (1991) 324 New England Journal of Medicine 889 at 889.
[420] At 890.
[421] N Kuldeep and others "Approximately One In Three US Adults Completes Any Type of Advance Directive For End-Of-Life Care" (2017) 36(7) Health Affairs 1244 at 1244.
[422] At 1245.

highlighted findings from the study included that people 65+ had a higher completion rate (45.6%) than younger adults (31.6%). For the 65+ age group the highest completion rates were among patients in hospice or palliative care (59%) and patients in nursing homes (50.1%).[423]

An interesting finding was that over the 6-year period of the study the proportion of people with a completed AD did not appear to have changed; the number was constant with only a nominal percentage difference between patients and healthy adults completing an AD;[424] patients with chronic disease (38.2%) and healthy adults (32.7%).[425]

Other useful points included that the healthcare providers have not promoted the ADs believing they had failed to live up to their potential. The legal formalities requiring an AD to have two witnesses to complete the documents was seen as a potential barrier for the vulnerable patient. It was found there could be improvements around the number of conversations and discussion of ADs that lead to a completed written form including goals and preferences that was then accessible to healthcare providers caring for a patient at end-of-life.[426]

Further observations were made around the importance of an AD to offer patients a way to avoid unwanted care in the event of serious illness or incapacity and that patients with an AD were less likely to die in hospital.[427] The ADs were viewed as a key component of high-quality ACP with the completion rates remaining a national priority.[428]

The study noted that efforts to increase completion rates of ADs should be targeted to those most likely to benefit[429]and that levels of use had increased where there was legal and educational promotion of the AD.

---

[423] At 1247.
[424] At 1250.
[425] At 1248.
[426] At 1249.
[427] At 1244.
[428] At 1250.
[429] At 1249.

It is older people who will want to know more about their choices as they age and targeting the group of people most likely to benefit from an AD is a good use of resources to increase the rate of completion.[430] It is very important that people are asked about what they want and do not proceed on anecdotal evidence or social opinion.

Applicable points for consideration in New Zealand are that there is interest in ADs from healthy adults and people with health issues alike which would indicate having an AD operating mainly within the health arena is much too limited. Promotion of ADs needs to include legal and health in promotion and there should be a priority to increase the use of ADs as an important component of ACP.

In 2016 a national survey of 4028 people between the ages of 50-89 years looked at the health, work and retirement status of older adults in New Zealand. While the study was more focused around ACP, certain parts of the study are relevant to this discussion. From the survey only 30% of the recipients had completed an EPOA, 7% had completed a living will (AD) and 4% had completed an AC Plan. The study identified a number of possible reasons for these low rates, including a lack of knowledge of the options that exist for people, subject avoidance around illness and death, perceptions around the relevance of the documents and limits on the time available to discuss these with a health professional.[431]

In the US studies an AD is clearly identified as an important component of ACP and is promoted in national policy. ACP in New Zealand is promoted with government funding but it is a newer concept than in the US. While an AD is a major part of ACP it is not well known, has few guidelines and its purpose is generally unclear.

Recommendations for improvement

There are a number of areas of concern within the current legal and health systems that may act as a barrier for the drafting, activation, and subsequent use of an AD. These barriers are in direct contradiction to individual rights inherent in New Zealand's legislation, in particular the NZBORA, the Human Rights Act, the PPPR Act, the HDC

---

[430] Emanuel and others, above n 421, at 895.

[431] Wendy Brown, Donald Baken and Christine Stephens "Advance care planning in New Zealand: A qualitative study of the motivators and barriers to uptake" (2021) 40(2) Australas J Ageing 1 at 64.

Code and the common law. The writer has identified some barriers that may impact on whether an advance directive will be honoured, including lack of appropriate legislation and guidelines, and a lack of knowledge.

Proposed legislative changes

The PPPR Act does not provide a clear and connected legal framework for EPOAs or ADs; in particular, the legislation does not provide judicial direction, guidance or an adequate review process, nor does it provide sufficient clarity, certainty or protection for people who no longer have capacity.

Fit for purpose legislation and supporting guidelines would provide the necessary protections for the elderly without capacity, address many of the concerns raised around alleged misuse of EPOAs, provide guidance for the healthcare providers around the use of ADs and ensure there is protection for user of the AD.

The area of mental capacity law is to be reviewed. The New Zealand Law Commission review of Adult Decision-making Capacity Law was listed on 6 October 2021, the terms of reference for the review have been published, and public consultation is expected to occur in 2022 with a report to the Minister of Justice by the end of 2023.[432]

A report updating New Zealand's law and practice in relation to mental capacity was completed for the New Zealand Foundation in 2016.[433] The report recommends revising mental capacity legislation that is supported by a code of practice providing guidance for all users. From that report Alison Douglass, with two other editors, have produced an up-to-date book as a New Zealand guide for doctors and lawyers which provides much needed commentary and a review of the New Zealand situation from both the medical and legal perspective with professional guidance for health practitioners, lawyers set out as a Toolkit for Assessing Capacity.[434]

---

[432] Law Commission inquiry (11 February 2022). <lawcom.govt.nz>

[433] Douglass, Alison Mental Capacity: *Updating New Zealand's Law and Practice* (New Zealand Law Foundation, 2016).

[434] Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Wellington Press 2020).

There is recent, comparable comprehensive legislation and guidelines developed in international jurisdictions that can provide New Zealand with examples of how best to assess and develop legislation.[435] Updated legislation will need to accommodate a changing world, reflect New Zealand society and obligations under te Tiriti o Waitangi, and comply with international and domestic obligations such as CRPD, the NZBORA, and the Human Rights Act.

New Zealand is a multicultural society with an indigenous people. Any changes to the legal framework need to be both pragmatic and workable, and would include specific guidance and rules around ADs.[436] Rather than relying on ethics, codes and guidelines, there needs to be certainty around the applicable legal standards. New legislation and guidelines must be accessible for all users including legal and health workers, families and whanau, and service users, and need to include education for everyone.[437]

Being pragmatic and workable includes an understanding of the associated benefits and drawbacks of a small population. Having 65+ age group numbers in the thousands rather than the millions is a benefit; having a limited tax base for the funding of all the wish list could be considered a drawback.

Changes must look to the future rather than be drafted to simply resolve past problems; this change must come from factual inquiry and empirical research rather than opinion evidence that fails to identify or address the actual issue that would be highlighted with quality research. Five yearly reviews of legislation would be introduced over a phased period, with some parts of the legislation being prospective only to allow the research to impact this development over time, keeping the legislation relevant and applicable in a changing environment.[438] The MCANI provides a modern and practical example of fit for purpose legislation around the introduction of ADs where s 11 is highlighted as

---

[435] MCA, MCANI, and Australian developing legislation and interpretation.

[436] Mark Tan Liak Min "Consideration for Introducing Legislation on Advance Decisions in Malaysia" (2018) 10 Asian Bioethics Review at 87.

[437] At 92.

[438] Judith AC Rietjens and others "Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?" (2009) 6 Bioethical Inquiry 271 at 274.
In 1990, the Netherlands government appointed a commission (Remmelink) to research issues such as the frequency and characteristic of end-of-life decisions around the euthanasia legislation that had been introduced. 5 yearly reports have allowed the legislation to develop based on empirical research.

prospective legislation. The intention is to allow the common law to develop case law, ensuring legislation remains fit-for-purpose and does not require constant amendment.[439]

The Operation of an AD

The new legislation would be based on statutory principles around capacity and best interests with a single capacity test applying throughout the legislation.[440]

An AD would be clearly defined and would no longer operate under the HDC Code; it would operate under the main legislation. The 'advance directive' would be renamed as an 'advance health directive' which is a better description, and would avoid confusion over the use of 'AD' for Alzheimer's disease or assisted dying under the End-of-life Choice Act 2019.[441] The legislation would give guidance on the making of an AHD, updating and cancelling, what is required for a valid and applicable AHD, the responsibilities of the healthcare professional when an AHD exists, and what to do if there is a disagreement with a comprehensive set of guidelines. In this paper I will continue to refer to advance directives as AD.

For the AD, where there were questions arising around its use or possible use, the first pathway for resolution would be a base meeting with all persons involved to try to resolve the issues raised. Where there was no agreement reached at the base meeting the matter would be moved to a Tribunal with fast and easy access, then to the Family Court for determination of the unresolved issues. This is expanded later in this paper.

A suggested standard form for the AD would be annexed to the guidelines with a checklist to apply for the AD to be completed within the legal setting and/or within the AC Plan.

The EPOA would be renamed as an LPA, to modernise the language to represent the intention of the document. The EPOA and AD and would by linked in the legislation again with clear guidelines for use.[442] The current signing provisions for an EPOA would be less strict to allow people to complete their own documentation from an online form;

---

[439] MCANI, s 11.

[440] MCANI is preferred.

[441] Ministry of Health "End-of-life Choice Act 2019". <health.govt.nz/our-work/life-stages/assisted-dying-service/end-life-choice-act-2019>

[442] MCANI is preferred.

a medical form would be completed at the time the EPOA was witnessed. The witnessing would not require a person to attend a legal office or be limited to a list of authorised persons. The EPOA would be registered to activate its use. In 2000, the New Zealand Law commission did consider a centralised registration system for EPOAs but rejected this believing that the ease of identifying if an EPOA existed did not outweigh the expense and loss of privacy.[443]

While any review of mental capacity law will need to consider a specific New Zealand focus on te Tiriti o Waitangi, CRPD and engaging in a multicultural society, the extensive brief and inquiry made by the Bamford Report in Northern Ireland should not be overlooked. The findings from that report will not be completely foreign to the issues in New Zealand and could be used for relevant input where appropriate; it is often not necessary to begin from scratch when there are wise learnings that are easily accessible.

A small research unit could be commissioned (like the Netherlands Remmelink Commission) with the private sector involved in the design and research. Any changes made in the area of mental capacity will be large and will affect a wide sector of people including people with dementia, acquired brain injuries, neuro-disabilities including learning and intellectual disabilities, mental health needs, other neurological or physical disabilities or health needs that affect their decision-making abilities.[444] The research would inform the development of the new legislation from a factual base with five-yearly reports.

New Zealand has an opportunity to develop its mental capacity law that incorporates comparable international models within a New Zealand framework to apply to a New Zealand society.

What might this look like?

Unlike the United Kingdom where a specialist Court of Protection was set up as part of the MCA legislation, the Family Court is a specialist court operating within the

---

[443] Rachel Kent "Misuse of Enduring Powers of Attorney" (2003) 34(3) Victoria University of Wellington Law Review 497 at 504.

[444] New Zealand Law Commission "Review of Adult Decision-making Capacity Law". <lawcom.govt.nz>

jurisdiction of the District Court.[445] The Family Court would remain the specialist court to uphold the legislative framework for capacity and would continue to make orders for those who no longer have capacity by way of personal orders and property orders. It would also address the issue around deprivation of liberty for people who no longer have capacity to consent as is included in overseas legislation.[446] In Appendix 1 the proposal is presented in a diagram.

The capacity legislation format under which the Family Court would have authority may best be suited to the Queensland model. Queensland has legislation in PAA and GAA. The first provides the legal framework for EPOAs and ADs; the second provides the operational framework, with comprehensive guidelines in place. New Zealand would have a similar structure with the Mental Health (Compulsory Assessment and Treatment) Act 1992 [MHA] as the third piece of legislation to apply under the Family Court. The MHA has recently published guidelines (2020) providing an interface between medical treatment and legal interventions.[447] The guidelines are comprehensive and have taken into account the experiences of people who had been involved in the system and their family and whanau with a rights-based approach to treatment, while acknowledging obligations under te Tiriti o Waitangi.[448] The writer understands they have been well received by practitioners.

The meeting

The situation when an AD (or EPOA) is to be used may indicate a person is elderly, no longer has capacity and is entering their end-of-life journey towards death. At this point where there are issues that arise around the use of the documents or other issues, the first resolution stage would be for clinicians, family/whanau, lawyer for subject person, hospital ethics or administrative committees and others (this could include district inspectors) to try to resolve these issues together by way of a formal meeting. The outcome of the meeting would only record who attended the meeting and whether there was agreement/partial agreement or no agreement reached. Where there is no agreement or a partial unresolvable agreement the matter would move to a Tribunal.

---

[445] Courts of New Zealand "Structure of New Zealand Courts". <teara.govt.nz/en/diagram/33933/structure-of-new-zealand-courts>

[446] MCANI have deprivation of liberty in their legislation.

[447] Ministry of Health "Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992" (2020) at 2.

[448] At 1.

The Tribunal

The Tribunal would provide a simple, fast and efficient way to access a flexible resolution forum (meetings could be at a hospital) to address issues that were not able to be resolved in the earlier discussions. Issues could include the determination of an AD as to validity and applicability, or particular situations around an EPOA. The Tribunal[449] would operate in a similar way to the MHA Tribunal and may include an ethics or hospital review member, the primary health care provider, welfare guardian, family/whanau, patient principal care giver, legal representatives, and others as required. The Tribunal would record who attended, the outcome of the meeting, the issues resolved and the issues that were remained outstanding.

The Family Court

Where no agreement was reached at the Tribunal level, the matter would be immediately transferred to the Family Court for urgent determination of the outstanding issues. The Family Court would have hearing time allocated each week for matters as required. The hearing would be led by a Family Court Judge and could take place at the hospital, the rest home or other relevant place.[450] Where there is no immediate Judge available, or in smaller regions, the hearing could be undertaken by video link. The number of hearings is likely to be low but would grow over time as more ADs were completed. The Family Court would retain the jurisdiction for determining capacity, a hearing would combine submission only or include cross-examination if required.

While the above would apply to urgent matters arising for the patient towards their end-of-life, currently there is no provision for a without notice application to be made to the Family Court under the PPPR Act, nor is there provision for the urgent appointment of lawyer for subject person when required. After consideration of the statutory provisions of the PPPR Act, Judge Burns found:

> *Taking all of these sections and rules together in combination I conclude that there is no power for the Family Court to grant an application filed on a without notice basis. However, I consider that there is jurisdiction for the Court to make an interim order under Pt 2 or a temporary order under Pt 3 of the Act without the subject*

---

[449] Courts of New Zealand, above n 450, at 1.

[450] Mental health hearings are often held at other venues.

> *person being served but conclude that the Court can only do so after a lawyer for the subject person is appointed, and in a position to be heard.*[451]

Without these provisions, a person who is in hospital and can no longer return home, is without the requisite capacity and with no EPOA or AD in place, is often transferred into a residential care facility under HDC Code s 7(4) until orders can be made; this can be a number of weeks later. The urgent appointment of a lawyer for subject person would be made with extended powers of investigation. The Family Court would also address deprivation of liberty.[452]

Office of the Public Advocate and Inspectorate

An Office of the Public Advocate and Inspectorate [OPAI] would be set up and operate under the Ministry of Justice [MoJ]. This office would act as watchdog for people who have lost capacity. Services could be contracted out to trustee companies to operate. The OPAI would appoint an advocate for a person who does not have anyone to act for them when they have lost capacity and need representation. Appointment of a representative could be at first meeting or Tribunal stage and at any Family Court hearing.

There is an increasing number of people without capacity or who with partial capacity who do not have anyone to act on their behalf. There can be many reasons for this including where family are living overseas, where family are not prepared to take on the role, where the person is very old and family and friends are no longer alive, or where family or friends are simply not suitable for the appointments. There are a few organisations and various Trusts providing this service but they can be hard to locate and usually have a high workload.[453] However, while this is a helpful option, it is not a sufficient long-term model to use with an increasing need for protection for people who no longer have capacity. The case has been made for a Public Advocate/Guardian office where these appointments can be made when required.[454] Such an appointment may also be relevant in some cases where an AD is to be activated.

---

[451] *Re MJD PPPRA – [interim and temporary orders]* [2013] NZFC 2706, [2013] NZFLR 911 at [19].

[452] Fisher and Anderson-Bidois, above n 310, at 19. It is likely only 37.7% of incapacitated ARC residents have a correct legal authority for their placement.

[453] Wellington Welfare Guardianship Trust is a Charitable Trust operating from Wellington. <welfareguardians.nz>

[454] Fisher and Anderson-Bidois, above n 455, at 83 [6].

The OPAI would be the place where all EPOAs would be registered to be activated; no EPOA could be used unless registered. At the point of registration an EPOA would be given an FAM number as per a Family Court application with the initial appointment for a three-year period. Property managers would have to file financial reports as per a PPPR s 31 appointment. The attorney would be required to undergo online training at this point and to sign a consent to appointment form confirming they understand the role and what is required. The penalties for non-compliance would be strengthened and would include Criminal charges for theft of money and property. Registration of EPOAs would be largely made online.

The issue around enforcement needs careful consideration so penalties are appropriate and useable. For example, when the amendments to the PPPR Act were made in 2007 the signing provisions for EPOAs were strengthened; one alleged area of abuse was the unauthorised use of the subject person's funds by property manager's which occur after the making of the EPOA. There is a lack of sanctions currently available to the Court and essentially no framework ensuring the supervision of a property manager. If a property manager fails to keep records as required the offence committed is liability for a summary conviction and a fine not exceeding $1,000.[455] This is the same situation where financial statements are not filed as required. [456] If a property manager uses the subject persons property and money, the two possibilities for the Court to consider would be a criminal prosecution or contempt of Court. Neither option offers the protection that might be expected. For a criminal prosecution for a breach, the fine is very small and where the Police may wish to take a prosecution, the Solicitor-General has discretion whether the case would be taken forward and if so, what the charges might be. For contempt of Court there must be an order that has been made or undertaking that has been given to the Court before contempt can exist.[457] The Court cannot, on the plain wording of s 16 enforce its own order by a contempt application. The Solicitor-General may be satisfied that there is a high degree of public interest for a prosecution; in many cases the threshold will not be reached and no prosecution will be taken.

---

[455] PPPR Act, s 99C.
[456] PPPR Act, s 45(4).
[457] Contempt of Court Act 2019 s16.

Registration also needs careful consideration. A register was not supported by the New Zealand Law Commission for the earlier PPPR amendments made but may have been influenced at the time by the Queensland Law Reform Commission possibly who had just completed their review and decided against introducing registration due to the cost, invasion of privacy, delay, bureaucracy and inability to detect or deter fraud.[458] Any system for registering an EPOA needs to be simple and useable, and provide to protection for the person who has lost capacity, without being absorbed into a government bureaucracy. These services could be contracted to a trustee corporation to operate. The Queensland AHD document has clear instructions for the person that their family and doctor should know of the AHD held and that the document should be reviewed regularly. There is a national register does operate for the MCA and MCANI, for LPA.

The Inspectorate

The inspectorate section of the OPAI would be similar to the mental health district inspectors. The purpose of the role would be to have oversight of the health and legal systems and ensure the systems and services between health, legal, residential care and community care are linked. It would provide checks and balances within these services, investigate complaints, and follow up on dementia care patients. Inspectors would also regularly inspect and review residential care facilities and institutions.[459] Currently the Chief Ombudsman monitors facilities where people are not free to leave at will, such as dementia care facilities. Inspectors could refer matters to the Tribunal or the Family Court. A small research unit would operate to develop and review systems and results that would inform future changes. This research or projects could be undertaken under contract or in partnership with universities.

EPlatforms

EPlatforms would be an integral part of any changes. While EPlatforms are already operating individually for healthcare and legal; there will need to be a linked best practice standard to access and manage information.[460]

---

[458] Kent, above n 446, at 514.

[459] Fisher and Anderson-Bidois, above n 457 at 84 [13].

[460] Helen Lunt and others "Electronic informed consent: the need to redesign the consent process for the digital age" (2019) 49(7) Internal Medicine 923 at 927.

Another simple use of technology has been seen to increase the completion rates of ADs. A study in the US considered specifically how technology could be used to increase the uptake for the completion of ADs. The first action came with computer-generated reminders that were sent to the physician to remind them to have their patients complete an AD. The result was compared to a control group where no reminders were sent. The rate of completion of ADs increased sixfold from 4% to 24%. In the second stage of the study, in addition to the reminder to physicians, forms and other materials were sent directly to the patients. This resulted in the completion rate for the ADs increasing by a further 14%.[461]

While there are concerns raised around the potential loss of face-to-face interactions with computer use, it has been found that computer-based education outperforms traditional text-based learning, even with older adults.[462]

The use of modern, connected technology is important in the development and use of EPOA, ADs, AC Plans and in ACP. EPOAs and ADs could be completed online, and electronically witnessed and certified as to capacity by an attached GP certificate. Where there was any doubt as to capacity a certificate from a practitioner specialising in capacity assessments would be required.

---

[461] Michael J Green and Benjamin H Levi “The era of ‘e’: The use of new technologies in advance care planning” (2012) 60 Science Direct Nurse Outlook 376 at 377.

[462] At 380.

Lack of knowledge of Advance Directives

For users

ADs are not well known or well used in New Zealand.

The Age Concern home page has information on ACP and EPOAs, but there is no mention of ADs;[463] the Super Seniors website has information on EPOAs but no information on ADs;[464] the Healthy Ageing Strategy published by the Ministry of Health does not include any reference to the PPPR Act in its Action Plan Ageing Well goals. The writer finds this surprising and somewhat reflective of the current lack of integration between health and legal.[465] There is little research undertaken in New Zealand around ADs and EPOAs, with no clear information available about their use. It is important to connect with the people who are the current and future users of ADs.

Studies have made it clear that older people (65+) want to know about their future care choices; completion of ADs is higher in this age group. In New Zealand it is not difficult to identify and contact them, to encourage the use of EPOA and ADs and to ensure people have the appropriate knowledge with which to make their decisions.

In New Zealand, at 65 a person starts receiving a government superannuation payment on application to the Ministry of Social development (MSD). The letter confirming this payment gives information about access to a Super Gold Card for discounts on services,[466] but, surprisingly, no information is included about other things that may be wise to consider during the next part of a person's life, such as the need to have an EPOA or an AD in place. In 2001 58,000 New Zealanders turned 65, the group is not hard to identify. Doctors report that 20% of their patients are aged 65 or older.[467]

Sabatino has suggested five actions where the public lacks understanding of ADs: provide written information to patients concerning their rights to make decisions about medical care and the right to have an AD; develop and maintain written policies and procedures and make them available on request; document whether or not the patient has

---

[463] Age Concern New Zealand "Money and legal". <ageconcern.org.nz>

[464] Ministry of Social Development Office for Seniors. <superseniors.msd.govt.nz>

[465] Ministry of Health "Healthy Ageing Strategy" (2016).

[466] Ministry of Social Development Office of Seniors. <supergold.govt.nz>

[467] G Young, A Douglass and L Davison 'What do doctors know about assessing decision-making capacity? (2018) 131(1471) NZMJ 1471 at 60.

executed an AD; comply with the requirements of state laws respecting ADs; and educate staff and community.[468]

The writer supports a national target for increasing the use of EPOA, ADs and AC Plans. Information would be provided initially to the new superannuation recipients and followed up by GPs. The GPs would follow up with their patients for five yearly intervals. The New Zealand Law Society [NZLS] would promote Wills, EPOA and ADs. A national advertising campaign would target the 65+age group.

For doctors

Although education for the medical profession is ongoing, one of the areas identified where more education is required is around capacity assessments. Doctors are expected to complete assessments and give advice in an area where there is uncertainty as to what evidence is required.[469]

A survey was undertaken in 2015 to see what doctors knew about assessing decision-making capacity.[470] The study reported that 31% of GPs and 33% of hospital doctors were not confident to complete a capacity assessment for a treatment decision, to a standard they would be prepared to present in Court.[471]

While it was noted there was a low response rate for the survey, the survey showed that the doctors who responded lacked knowledge and confidence around capacity assessments; this was due to time pressures, a lack of understanding of relevant law, pressures dealing with families having preconceived ideas of capacity, a lack of understanding about end-of-life care issues, family information conflicting with patient information and family conflict.[472] Ongoing professional education would assist.

For lawyers

There is little training for lawyers in the field of AD with the subject usually raised in NZLS CLE seminars for Wills, EPOAs and Trusts. In a recent legal seminar, an AD was

---

[468] Charles P Sabatino "The Evolution of Health Care Advance Planning Law and Policy" (2010) 88(2) The Millbank Quarterly 211 at 215.
[469] Young, Douglass, Davison, above n 470, at 58.
[470] At 59.
[471] At 61.
[472] At 62.

only mentioned under ACP; there was no mention or advice given to lawyers about completion of ADs.[473] There needs to be training for both medical and legal around the area of use of ADs whether under the PPPR Act or the HDC Code. The NZLS may wish to address the subject of ADs in a future seminar.

The lawyer for subject person role has no ongoing formal training after appointment other than their own endeavours. The role is about the protection of the vulnerable person; this is different from the lawyer for child role which is about the welfare and best interest of the child.[474] There is mandatory and ongoing training in place for lawyer for child appointments but not for lawyer for subject person. A similar training programme, particularly around the area of assessment of capacity, would provide lawyers with the necessary training to be able to more competent to fulfil this important role.

Where a person instructs their solicitor to draft an EPOA and an AD, the form of the EPOA is prescribed, but the solicitor has no prescribed form or guidelines to follow for the drafting of the AD. It is usual for a firm to have an AD precedent, but this tends not to provide the client with information around the options they may wish to consider. It is also doubtful whether an older precedent would still apply; it might be too vague, too general, and difficult to interpret or may use inappropriate language to describe a situation.[475]

While not providing a prescribed form for an advance directive, the MCA does have a long form and short form to consider, and provides a formal checklist for use by solicitors who are taking instructions for an advance decision. The Family Court would be well served if each process around the PPPR Act was supported by a checklist, and particularly in the area of court orders, EPOAs and ADs.

Summary

The lack of knowledge and understanding of ADs reflects a lack of legislative guidance and support.

---

[473] Although this was a legal training seminar provided by NZLS CLE there was no reference made to the Legal Profession involvement relating to ADs.

[474] COCA, ss 3, 4 & 5.

[475] Collier, Coyne and Sullivan, above n 410, at 84.

It is important for law and medicine (including the Courts, hospitals, rest homes, people and families/whanau) to be more connected in the development of legislation for EPOA and ADs, with applicable guidelines that will also apply for documents completed within ACP and to include AC Plans. This would ensure a process is in place for people to make their own choices and preserve their right to autonomy and dignity at their end-of-life.

As Atul Gawande has said:

> *'One essential characteristic of modern life is that we all depend on systems – on assemblages of people or technologies or both – and among our most profound difficulties is making them work'.*[476]

System excellence will not be achieved by optimising separate parts; all components need to fit together.[477] Within the wider vision of fit for purpose legislation and systems for capacity law, at all times the focus must remain on the rights of the vulnerable person without capacity with the questions to be asked: what is their vision? what have they asked for? and what else do they need? It is their end-of-life journey, how can they be respected?

---

[476] Atul Gawande, *The Checklist Manifesto How to Get Things Right* (Profile Books Ltd, London, 2011) at 184.

[477] At 185.

Conclusion

The issues around the loss of capacity, medical and care treatment at end-of-life and the use of ADs are complex and often without an easy process for resolution. An AD is a choice about treatment that aligns with the person's own values and wishes; that choice is then extended to a future time. Dworkin's view is that the person making the AD has considered and given thought to the choices made with an expectation the directions will be followed at a future time and their autonomy upheld, even if this conflicts with best interest decisions others may have chosen for them. In law where an AD is valid and applicable it must be followed.

An AD is a very personal document and will usually be used for the period near the end of a person's life. Every person has a right to refuse treatment and has a right to choose a natural death. For some retaining a degree of autonomy and self-determination is very important, for others it is not as important and for some it has no importance. A person's culture, religion, family and personal values and beliefs will impact decisions that will be made. In a multicultural society the conversations held must be sensitive and differences respected. For Māori, beliefs around death and dying and the collective values of whānau may better relate to supported decision making around end-of-life wishes and decisions.

This paper has focused on the 65+ age group; a group who have a strong desire to be involved in making their own medical decisions. This expressed interest has not always resulted in ADs being completed and while the number is not known it appears to be low. Overlaying the low rate of completion there is a clear lack of knowledge and understanding around the area of EPOA and ADs. The levels of uptake for ADs has improved overseas by targeting the older age group with reminders sent to health care providers and information then sent directly to the target group. In New Zealand approximately 58,000 people turn 65 in any one year (2021), educational information on EPOAS and ADs could be made available; the legal and medical professions would follow up with their clients 65+.

An increased life expectancy for the 65+ age group brings an increasing risk of cognitive impairment, loss of capacity and a life spent with some disability. With the increase in dementia the ensuing fragility can mean a long and slow decline to death. For some the expectation of a long and healthy life may be different in reality. A loss of capacity will change a life forever, and unless decisions and choices have been made earlier there is no certainty about the choice that will then be made on that person's behalf.

Recommendations have been proposed to increase the certainty that an AD will be honoured. This begins with a comprehensive statutory framework that connects and consolidates all areas of capacity and provides a single capacity test. The legislation would operate with guidelines and checklists that can be used by everyone. While the Queensland format of legislation is preferred as a more useable structure for New Zealand the MCA and MCANI both have useable formats.

Legislation would be prospective to allow an ever-changing environment with the user group for ADs and end of life choices changing each generation; their needs, wants and focus will vary. Legislation would develop with research directing changes rather than individual experiences of an issue. The AD would have a form, within the legislation, that may or may not be used. An online format, simpler signing and witnessing provisions, a register to active an EPOA (an AD could be registered if wished). Access to the AD through medical records, family, ARC and other would ensure that in most situations there would be knowledge of whether there was an AD. The AD would be reviewed regularly to remain current.

What is important in the area of end-of-life care is a multidisciplinary approach to the development of policy and systems with a wide range of organisations involved. The term multidisciplinary, when used in the health arena often does not appear to include legal as part of that approach. The medico view often expressed is that matters can become too legalistic. The legal view can be that health needs the law to set the legal framework to provide clarity, certainty and protection for vulnerable people.

Where both medical and legal are involved, the continuing development of the AD and ACP is supported; as is supported decision-making. It has always been important that people without capacity have protection.

Whether an AD is to be honoured will depend on many factors; there are no guarantees. If a person has an accident or is involved in an emergency event, the decisions made at those times may not be what the person would choose. In other circumstances an AD should provide certainty that the directions given will be followed. While currently undervalued ADs do provide a choice option for people outside the health system; their use must be actively promoted.

Any changes to legislation and practice must uphold the obligations to te Tiriti o Waitangi and such international treaties such as the CRPD. In all inquiries and discussions, it is the people who need to have input into what they want, need and value; they must be consulted and become part of the process. The AD is part of this discussion as well.

It is always time to talk; at times it is good to talk about life and sometimes it is good to talk about dying. While dying is a certainty for everyone, dying well may not always provide the same degree of certainty.

“If I lose capacity, will my AD be honoured?” The answer today is maybe, tomorrow it may change.

Bibliography

A. Cases

1. New Zealand

Auckland Area Health Board v Attorney-General [1993] 1 NZLR 235.

CA v EA [2017] NZFC 7045.

Chief Executive of the Department of Corrections v Canterbury District Health Board and All Means All [2014] NZHC 1433.

Corbett v Patterson [2014] NZCA 274.

Re F (No 3) FC Levin PPPR 031/020/91, 31 January 1992.

Hohipa v R [2015] NZCA 73.

KR v MR [2004] 2 NZLR 847.

McFadzean v Moleta [2013] NZHC 1601.

Re MJD PPPR – [interim and temporary orders] [2013] NZFC 2706, [2013] NZFLR 911.

NJF v MIF FAM-2008-063-759, Family FC Rotorua, 20 December 2010.

Seales v Attorney-General [2015] NZHC 1239.

Shortland v Northland Area Health Board Ltd [1998] 1 NZLR 433.

Re: Tony [1990] 5 NZFLR 609.

Re W [1994] 3 NZLR 600.

2. United Kingdom

Airedale NHS Trust v Bland [1993] AC 7890 (HL).

Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.

Bolitho v City and Hackney HA [1998] AC 232.

R v Bournewood Community and Mental Health NHS Trust, Ex p. L [1998] All ER 289.

P v Cheshire West v Chester Council and P v Surrey County Council [2014] UKSC 19.

Re C (Adult Refusal of Treatment) [1994] 1 WLR 290.

Re F (Mental Patient: Sterilisation) [1992] 2 AC 1.

Re H (Minors) [1996] AC 563.

Re T (Adult Refusal of Treatment) [1992] 4 All ER 649, [1992] 3 WLR 782; [1993] Fam 95.

3. Europe

Case C-19/04910 Supreme Court of the Netherlands ECLI:NL:PHR:2020:712.

HE v A Hospital Trust [2003] EWHC 1017 (Fam), [2003] 2 FLR 408.

Kings College NHS Foundation Trust v C and V [2015] EWCOP 80.

PC and NC v City of York Council [2013] EWCA Civ 478, [2014] 1 FAM 10.

4. United States of America

Re: Quinlan, 355A2d 647 (NJ 1976).

5. Canada

Carter v Canada (Attorney-General), 2015 SCC 5, [2015] 1 SCR 331.

6. South Africa

Stransham-Ford v Minister of Justice [2015] ZAGPPHC 230 (HCSA).

B. Legislation

1. New Zealand

Care of Children Act 2004.

Contempt of Court Act 2019.

End of Life Choice Act 2019.

Health and Disability Commissioner Act 1994.

Mental Health (Compulsory Assessment and Treatment) Act 1992.

New Zealand Bill of Rights Act 1990.

Protection of Personal and Property Rights Act 1988.

2. Australia

Guardianship and Administration Act 2000 (Qld.)

Powers of Attorney Act 1998 (Qld).

3. United Kingdom

Mental Capacity Act 2005 (UK).

Mental Capacity Act (Northern Ireland) 2016.

4. United States of America

Natural Death Act, California, 1976

C. Treaties, Conventions, Codes, Guidelines and other

Advance Care Planning A Guide for the New Zealand Workforce (Ministry of Health, August 2011).

Australian Government "National Framework for Reducing and Eliminating the Use of Restrictive Practice in the Disability Service Sector" (Department of Social Services, Canberra, 2014).

Department of Health "Mental Capacity Act (Northern Ireland) 2016 Deprivation of Liberty Safeguards Code of Practice" (November 2019).

Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996.

Mental Capacity Act 2005 Code of Practice (Department of Constitutional Affairs, 2007).

Mental Capacity Act (Northern Ireland) 2016 Code of Practice.

Ministry of Health "Mental Health (Compulsory Assessment and Treatment) Act 1992 Guidelines" (2020).

National Dementia Strategy Living well with dementia: a national dementia strategy 2009 (Department of Health, UK).

United Nations Convention on the Rights of Persons with Disabilities A/RES/61/106 (opened for signature 30 March 2007, entered into force on 03 May 2008).

United Nations Declaration on the Rights of Indigenous Peoples A/Res/61/295 (opened for signature 29 June 2006, entered into force 13 September 2007) 2007.

Queensland Government "Queensland Capacity Assessment Guidelines 2020 A guide to understanding capacity, capacity assessment and the legal tests of capacity under Queensland guardianship legislation" (2020).

D. Books and Chapters in Books

B Atkin (ed) *Personal Orders* (looseleaf ed, Lexis Nexis) at [7.823-7.826].

Angela Ballantyne and Chris Reid "Supported Decision-making" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Clare Barrett (ed) *Incapacity* (looseleaf ed, Westlaw) at [PP18].

Joanne Baxter "Māori Perspectives" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Sylvia Bell *Protection of Personal and Property Rights, Act and Analysis* (Brookers Ltd, Wellington, 2012).

Sylvia Bell and Warren Brookbanks "Decision-making and the Protection of Personal Property Rights Act 1988" in Kate Diesfield, Ian McIntosh (eds) *Elder Law in New Zealand* (Thomson Reuters New Zealand Limited, Wellington, 2014).

Blackstone's Commentaries on the Laws of England (Clarendon Press, Oxford, 1765) vol 1.

Lesley Brown (ed) The New Shorter Oxford English Dictionary (Clarendon Press, Oxford, 1993) 2 at 3542.

Berna Collier, Chris Coyne and Karen Sullivan (eds) *Mental Capacity, Powers of Attorney and Advance Health Directives* (The Federation Press, 2005).

Kate Diesfield, Ian McIntosh (eds) *Elder Law in New Zealand* (Thomson Reuters New Zealand Limited, Wellington, 2014).

M Donnelly *Healthcare Decision-making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, Cambridge, 2010).

Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

R. Dresser, "Advance Directives, Self -Determination and Personal identity" in C Hackler, R Mosely and D Vawter (eds), *Advance Directives in Medicine* (New York: Praeger, 1989) 155.

G Dworkin *The Theory and Practice of Autonomy* (Cambridge: New York: Cambridge University Press, 1988).

Ronald Dworkin *Life's Dominion: an argument about abortion and euthanasia* (Harper Collins, London, 1993).

Mark Fisher "Liberty and Placement in Care" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Atul Gawande *Being Mortal Illness, Medicine and What Matters in the End* (Welcome Collection, London, 2014).

Atul Gawande *The Checklist Manifesto, How To Get Things Right* (Profile Books, London, 2011).

Govert den Hartogh "The Authority of Advance Directives" in Denier Y, Gastmans C and Vandervelde A. (eds) *Justice, Luck & Responsibility in Health Care* (Library of Ethics and Applied Philosophy, London, 2013) 167.

Michael A Jones *Medical Negligence* (5th ed, Sweet & Maxwell, London, 2015).

Nuala Kane and Alex Ruck Keene "Capacity Law and the PPPR Act" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Alex Ruck Keene "Capacity and Health Care" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Kathryn Mannix *With the End in Mind How to Live and Die Well* (William Collins, London, 2018).

Ron Paterson "Advance Decisions" in Alison Douglass, Greg Young and John McMillan *Assessment of Mental Capacity. A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020).

Ron Paterson in PDG Skegg and Ron Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015).

Derek Parfitt *Reasons and Persons* (Clarendon Press, Oxford, 1986).

DD Raphael *Moral Philosophy* (2nd ed, Oxford University Press, Oxford, 1994) at 8.

Iris Reuvecamp and John Dawson (eds) *Mental Capacity Law in New Zealand* (Thomson Reuters, Wellington, 2019).

Neil J Salkind, *100 Questions (and Answers) About Research Methods,* (Sage Publications, Los Angeles, 2012).

Richard Scragg, *The Ethical Lawyer: legal ethics and professional responsibility* (Thomson Reuters, Wellington, 2012).

PDG Skegg and Ron Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015).

Allen W. Wood "What is Kantian Ethics?" in Allen W Wood (ed and translator) and others *Groundwork for the Metaphysics of Morals Immanuel Kant* (Yale University Press, 2002).

E. Journal Articles

Catherine Jane Bond and Karen Lowton "Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study" (2011) 40(4) Age and Ageing 450.

Wendy Brown, Donald Baken and Christine Stephens "Advance care planning in New Zealand: A qualitative study of the motivators and barriers to uptake" (2020) Australas J Ageing 1.

Rachel Z. Carter and others "Advance care planning in Australia: what does the law say?" (2015) 40 Australian Health Review 405.

Paula Case "Negotiating the Domain of Mental Capacity: Clinical judgement or judicial diagnosis?" (2016) 16(3-4) Medical Law International 174.

Kim Chandler, Ben White and Lindy Willmott "Safeguarding Rights to Liberty and Security where People with Disability are Subject to Detention and Restraint: A Practical Approach to the Adjudication, Interpretation and Making of Law (Part Two)" (2018) 25(4) Psychiatry, Psychology and Law 550.

Mathew Croucher "Geriatric medicine is becoming the core of hospital business" (2010) 123(1317) The New Zealand Medical Journal 7.

Matthew Croucher "Psychotropic medications for elders in residential care" (2008) 121(1274) The New Zealand Medical Journal 7.

Alison Douglass "Rethinking necessity and best interests in New Zealand mental capacity law" (2018) 18(1) Medical Law International 3.

Rebecca Dresser "Dworkin on Dementia Elegant Theory, Questionable Policy" (1995) 25(6) Hastings Center Report 32.

Ronald Dworkin "Autonomy and the Demented Self" (1986) 64(2) The Millbank Quarterly 1.

Linda L. Emanuel and others "Advance Directives for Medical Care – A Case for Greater Use" (1991) 324 New England Journal of Medicine 889.

Susan Enguidanos and Jennifer Ailshire "Timing of Advance Directive Completion and Relationship to Care Preferences" (2016) 53(1) Journal of Pain and Symptoms Management 49.

Grant Gillett Sanctity of Life, A Sense of Life and Good Endings (2006) 6(2) Law and Justice Journal 243.

Jane Goodwin and others "Achievements and challenges during the development of an advance care planning programme" (2021) Australas J Ageing 1.

Michael J Green and Benjamin H Levi "The era of 'e': The use of new technologies in advance care planning" (2012) 60 Science Direct Nurse Outlook 376.

HC Hangar and others "Stroke patients' views on stroke outcomes: death versus disability" (2000) 14 Clinical Rehabilitation 417.

Benedict Hayhoe and Amanda Howe "Advance Care Planning under the Mental Capacity Act 2005 in Primary Care" (2011) 61 British Journal of General Practice 589.

R Horn "The French exception: the right to continuous deep sedation at the end-of-life" (2018) 44(3) Journal of Medical Ethics 204.

Agnieszka Jaworska "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value" (1999) 28(2) Philosophy & Public Affairs 105.

A Keene and others “Taking capacity seriously? Ten years of mental capacity disputes before England’s Court of Protection” (2019) 62 International Journal of Law and Psychiatry 56.

Rachel Kent “Misuse of Enduring Powers of Attorney” (2003) 34(3) Victoria University of Wellington Law Review 497.

Katherine R Kruse “The Jurisprudential Turn in Legal Ethics” (2011) 108 Scholarly Works 493.

N Kuldeep and others “Approximately One In Three US Adults Completes Any Type of Advance Directive For End-Of-Life Care” (2017) 36(7) Health Affairs 1244.

Cameron Lacey and others “The Hui Process: a framework to enhance the doctor-patient relationship with Māori” (2011) 124(1347) The New Zealand Medical Journal 72.

Phillipa J Malpas “Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand” (2011) 37(5) Journal of medical ethics 285.

Oliver Menzies and others “He Tūhononga Whaiaro: A Kaupapa Māori Approach to Mate Wareware (Dementia) and Cognitive Assessment of Older Māori” (2021) Journal of Applied Gerontology 1.

AS Kessel and J Meran “Advance directives in the UK: legal, ethical, and practical considerations for doctors” (1998) 48(430) British Journal of General Practice 1263.

D Lanham and B Fehlberg “Living Wills and the Right to Die with Dignity” (1991) 18 Melbourne University Law Review 329.

Helen Lunt and others “Electronic informed consent: the need to redesign the consent process for the digital age” (2019) 49(7) Internal Medicine 923.

Gerard Lynch, Catherine Taggart and Philip Campbell “Mental Capacity Act (Northern Ireland) 2016” (2017) 41(6) BJPsych Bulletin 353.

R Mackenzie and J Watts “Mind the gap: the Deprivation of Liberty Safeguards in the amended Mental Capacity Act 2005”, (2010) 15(1) Tizard Learning Disability Review 5.

Phillipa J Malpas “Advance directives and older people: ethical challenges in the promotion of advance directives in New Zealand” (2011) 37 J Med Ethics 285.

Dennis J. Mazur “Patients’ Willingness to Accept Life-Sustaining Treatment When the Expected Outcome is a Diminished Mental Health State: An Exploratory Study” (1996) 44(5) Journal of the American Geriatrics Society 565.

Oliver Menzies and others “He Tuhonoga Whaiaro: A Kaupapa Māori Approach to Mate Wareware (Dementia) and Cognitive Assessment of Older Māori” (2021) Journal of Applied Gerontology 1.

Mark Tan Liak Min “Consideration for Introducing Legislation on Advance Decisions in Malaysia” (2018) 10 Asian Bioethics Review at 87.

Rachael Mulheron “Trumping Bolam: a Critical Legal Analysis of Bolitho’s Gloss” (2010) 69(3) Cambridge Law Journal 609.

John Oetzel, and others “Managing Communication Tensions and Challenges During the End-of-Life Journey: Perspectives of Māori Kaumātua and Their Whānau” (2015) 30(4) Health Communications 350.

Robert S Olick “Defining Features of Advance Directives in Law and Clinical Practice” (2012) Medical Ethics 232.

Pam Oliver, Michael Wilson and Phillipa Malpas “Attitudes of New Zealand doctors and nurses towards legalising assisted dying” (2017) 130(1456) New Zealand Medical Journal 10.

Joel J Rhee, Nicholas A Zwar and Lynn A Kemp “Uptake and implementation of Advance Care Planning in Australia: findings of key informant interviews” (2021) 36(1) Australian Health Review 98.

Judith AC Rietjens and others “Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain?” (2009) 6 Bioethical Inquiry 271.

Louise Robinson and others “A qualitative study: Professionals’ experiences of advance care planning in dementia and palliative care, ‘a good idea in theory but …” (2013) 27(5) Palliative Medicine 401.

Arnold J Rosin and Moshe Sonnenblick “Autonomy and paternalism in geriatric medicine. The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation” (1998) 24 Journal of Medical Ethics 44.

Charles P Sabatino “The Evolution of Health Care Advance Planning Law and Policy” (2010) 88(2) The Millbank Quarterly 211.

Ash Samanta and Jo Samanta “Legal Standard of care: a shift from the traditional Bolam test” (2003) 3(5) Clinical Medicine 443.

Jeffrey l. Schnipper and others “ ‘Smart Forms’ in an Electronic Medical Record: Documentation-based Clinical Decision Support to Improve Disease Management” (2008) 15(4) Journal of American Medical Informatics Association 513.

William Silvester and others “Quality of advance care planning policy and practice in residential aged care facilities in Australia” (2013) 3 BMJ Supportive & Palliative Care 349.

Barry Snow “ACP Deployment: The New Zealand Experience” (2015) 5(2) BMJ Supportive Palliative Care A1.

Henricus Berend Speelberg and others "An evaluation of the contents of advance care plans and their use in patients admitted to a public hospital" (2020) 133(1526) New Zealand Medical Journal 55.

Mark R Tenelli "Pulling the Plug on Living Wills: A Critical Analysis of Advance Directives" (1996) 110 Ethics in Cardiopulmonary Medicine 816.

Cordelia Thomas "Refusal of medical treatment by way of advance directives" (2001) 3 Butterworths Family Law Journal 233.

Douglas B White and others "Life Support for Patients Without a Surrogate Decision Maker: Who Decides?" (2007) 147(1) Annals of Internal Medicine 34.

Wilmott, Lindy, White, Ben & Mathews, Ben "Law, Autonomy and Advance Directives" (2010) 18(2) Journal of Law and Medicine 366.

G Young, A Douglass and L Davison "What do doctors know about assessing decision-making capacity?" (2018) 131(1471) The New Zealand Medical Journal 1471.

F. Parliamentary and Government material

Advance Care Plan form. - <hqsc.govt.nz/assets/ACP/PR/ACP_Plan_print_.pdf>

Advance decision to refuse medical treatment under the Mental Capacity Act 2005 – long form reference EFP 42(3): 12/2016.

Age Concern New Zealand "Money and legal". <ageconcern.org.nz>

Department of statistics. <stats.govt.nz/information-releases/national>

The Health & Disability Commissioner "Code of Health and Disability Services Consumers' Rights". <hdc.org.nz/your-rights/about-the-code/>

Ministry of Health "Assisted Dying Service". <health.govt.nz/our-work/life-stages/assisted-dying-services>

Ministry of Health "Healthy Ageing Strategy" (2016).

Ministry of Health "Older people's health data and stats". <health.govt.nz/nz-health-statistics/health-statistics-and-data-sets/older-peoples-health-data-and-ststs/dhb-spending-services-older-people>

My Advance Care Plan & Guide: Plan the healthcare you want in the future and for the end of your life. <hqsc.govt.nz/assets/ACP/PR/ACP_Plan_print_.pdf>

Law Commission "Review of Adult Decision-making Capacity Law". <lawcom.govt.nz>

Ministry of Social Development Office for Seniors. <superseniors.msd.govt.nz>

Ministry of Social Development Office of Seniors. <supergold.govt.nz>

Solicitor’s checklist of points to be considered when drafting an advance decision to refuse medical treatment under the Mental Capacity Act 2005. Reference EFP 42(3): 12/2016.

Stats NZ “2013 Census Quickstats about people aged 65 and over”. <stats.govt.nz/infographics/people-aged-65-plus-living-in-new-zealand>

Stats NZ “Historic estimates and national population projections, 2014 (base) 2068”. <catalogue.data.govt.nz>

Stats NZ “National population projections, by age and sex, 2020(base)-2073.” <nzdotstat.govt.nz>

G. Reports

Advance Care Planning A guide for the New Zealand Workforce (Ministry of Health, August 2011).

Ageing and Indigenous Health in Aotearoa New Zealand Position Statements (Australasian & New Zealand Society for Geriatric Medicine, 2020).

Michael Bach and Lana Kerzner *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Commission of Ontario, October 2010).

Jane Casey and Andrew Steele *In Short Capacity – Practical Insights* (New Zealand Law Society Continuing Legal Education, September 2021).

Alison Douglass *Mental Capacity: Updating New Zealand’s Law and Practice* (New Zealand Law Foundation, 2016).

Mark Fisher and Janet Anderson-Bidois (eds) *This is not my Home A collection of perspectives on the provision of aged residential care without consent NZ Human Rights* (New Zealand Human Right Commission, June 2018).

Jane Goodwin and Nick Laing *Advance Care Planning – Issues for Lawyers* (New Zealand Law Society Continuing Legal Education Webinar, September 2019).

Jane Goodwin and Nick Laing *End-of-life Choice Act* (New Zealand Law Society Continuing Legal Education Webinar, August 2021).

Law Commission, *Misuse of Enduring Powers of Attorney* (NZLC R71, 2001).

Ma’u E and others *Dementia Economic Impact Report 2020* (University of Auckland, Prepared for Alzheimer New Zealand, September 2021).

Vladimir Stevanovic *Independent Life Expectancy in New Zealand* (Ministry of Health, 2013).

World Health Organization *Global Health and Ageing* (US National Institute of Aging, Geneva, 2011).

H. Dissertations

Wendy Brown "The Uptake of Advance Care Planning by Older Adults in New Zealand" (Master of Arts, Massey University, 2018).

I. Other resources

Advice given in August 2021 was the Court would consider translating the case after the summer recess. By email 3 August 2021 (NZLS).

Ageing and Indigenous Health in Aotearoa New Zealand Position Statement 24 (Australasian & New Zealand Society for Geriatric Medicine, 2020).

Ageing and Indigenous Health in Aotearoa New Zealand Position Statement 16 (Australasian & New Zealand Society for Geriatric Medicine, 2020).

Courts of New Zealand "Structure of New Zealand". <teara.govt.nz/en/diagram/33933/structure-of-new-zealand-courts>

Ronald Dworkin obituary The Guardian 14 February 2013.

Family Court Minute brief for lawyer for subject person (3 December 2021).

Kate Grundy *Dying Well* (ACP training paper, Christchurch, May 2021).

Law Commission inquiry (11 February 2022). <lawcom.govt.nz>

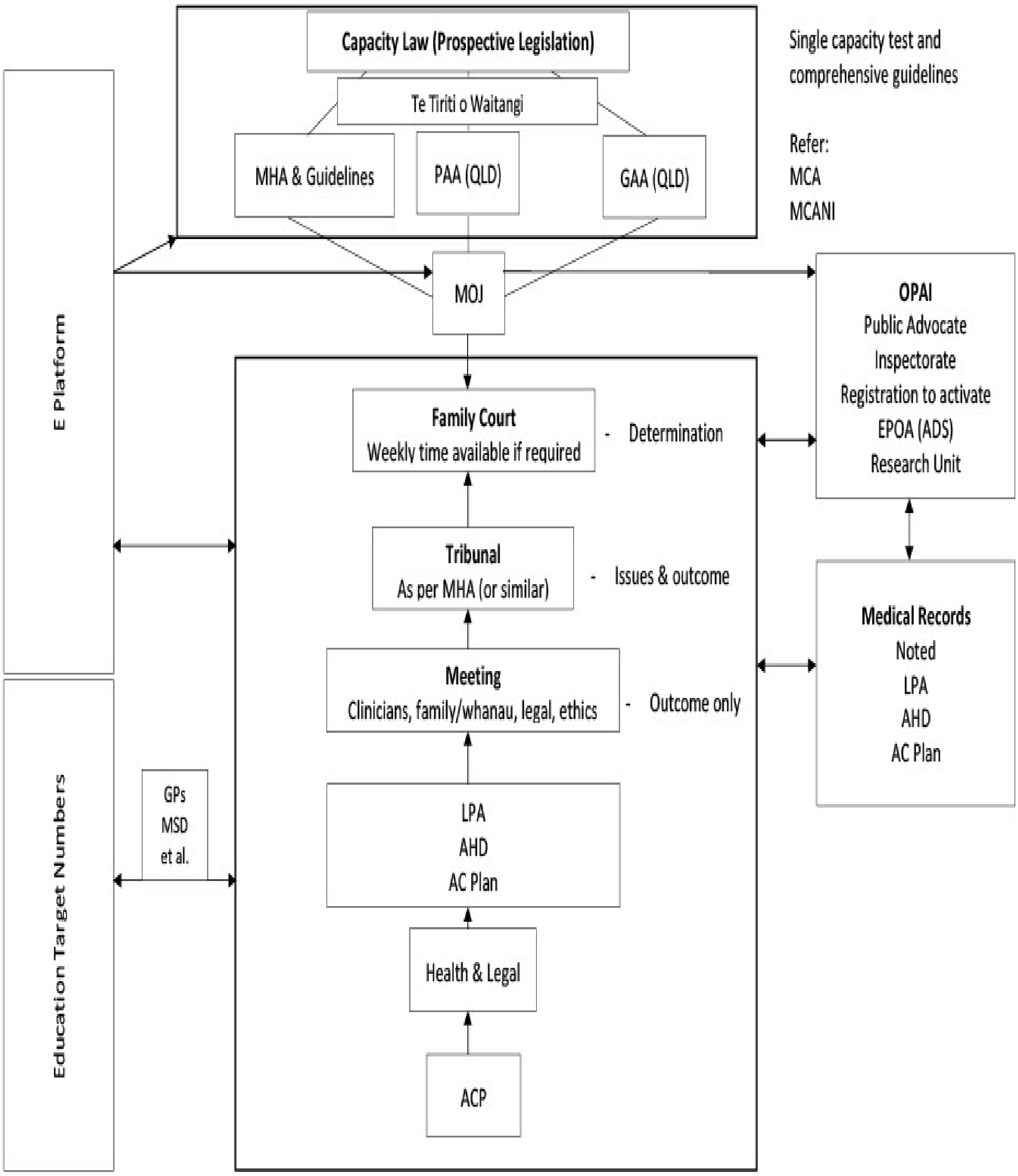
Ministry of Justice letter (Ref: 90590, number of applications filed under PPPR Act, by application type and year, 2016-2020) (obtained under Official Information Act 1982 Request to A Meates).

NZMA Code of Ethics for the New Zealand Medical Profession (2020).

Toronto Star 29 Aug 2019 RAF Casert and Aleksandar Furtula The Associated Press.

Wellington Welfare Guardian Trust. <welfareguardians.nz/documents/wellington>

Appendix 1


Capacity Law (Prospective Legislation)
Te Tiriti o Waitangi
MHA & Guidelines
PAA (QLD)
GAA (QLD)
Single capacity test and comprehensive guidelines
Refer:
MCA
MCANI
E Platform
MOJ
OPAI
Public Advocate
Inspectorate
Registration to activate
EPOA (ADS)
Research Unit
Family Court
Weekly time available if required
- Determination
Tribunal
As per MHA (or similar)
- Issues & outcome
Medical Records
Noted
LPA
AHD
AC Plan
Meeting
Clinicians, family/whanau, legal, ethics
- Outcome only
Education Target Numbers
GPs
MSD
et al.
LPA
AHD
AC Plan
Health & Legal
ACP

Glossary

MHA	Mental Health (Compulsory Assessment and Treatment) Act 1992
PAA (QLD)	Powers of Attorney 1998 (QLD)
GAA (QLD)	Guardianship and Administration Act 2000 (QLD)
MCA	Mental Capacity Act (England and Wales) 2005
MCANI	Mental Capacity Act (Northern Ireland) 2016
QLD	Queensland
MOJ	Ministry of Justice
LPA	Lasting Powers of Attorney
AHD	Advanced Health Directive
AC PLAN	Advanced Care Plan
ACP	Advanced Care Planning
EPlatform	A system that can link legal and health